

**PERSONALIZED MOBILE TOOLS TO SUPPORT THE CANCER  
TRAJECTORY**

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# **PERSONALIZED MOBILE TOOLS TO SUPPORT THE CANCER TRAJECTORY**

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I dedicate this dissertation to my family, Gabriel, Ari, Mike, Robin, and Yoni Jacobs, for  
your neverending support and love.

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## SUMMARY

Over 230,000 people in the United States are diagnosed with breast cancer annually [1]. Those individuals coping with cancer face a number of new health management tasks, such as managing symptoms and side effects and dealing with the emotional and financial consequences of the diagnosis and treatments [2]. These challenges can significantly impact patients' quality of life, particularly if they do not feel they have the knowledge or skills to cope with health issues as they arise [3].

Supporting individuals managing cancer and other complex health issues is a difficult process. Patients require comprehensive support, as the diagnosis not only affects one's physical health, but also has lasting effects on one's psychosocial wellbeing [4]. Further, the information needs of patients are continuously changing as they progress through various treatments and into post-treatment survivorship [5]. Finally, cancer care experiences are diverse, with patients experiencing different side effects and personal challenges [6]. Thus, a need exists for interventions that connect patients to information and resources that meets their specific needs. Existing tools typically focus on a small subset of goals or tasks, such as symptom tracking or exercise monitoring, placing the burden on patients to integrate information from disconnected sources and repeatedly find and incorporate new resources as their healthcare needs change.

In my research, I have developed new computing approaches for mobile health tools that consider the holistic and changing needs of individuals over time. To inform these systems, I have run a series of studies to understand how technology can better support patients throughout the cancer trajectory. While studies have identified a variety of patient challenges, few consider how individuals' priorities shift over time as their health changes. Through multiyear engagements with both breast cancer survivors and healthcare professionals, I first worked to understand the complexities of cancer care and patients' cancer experiences. Through this work, I created a comprehensive framework of the cancer expe-

rience, presenting a robust set of patient information needs and challenges, and identifying the scope of support necessary across common phases of breast cancer care.

These studies culminated in the design and evaluation of two novel mobile health systems: MyJourney Compass and MyPath. With the MyJourney Compass technology probe, I assessed how patients would adopt and engage with a mobile health tool as they progress through treatment and post-treatment survivorship. Often evaluations of health tools focus on behavior changes over a limited period of time. Through a yearlong technology probe, I confirmed that newly diagnosed patients were willing to adopt a novel mobile health tool into their daily lives, independent of factors such as age or technological expertise. Further, participants remained engaged with the system even after finishing treatment, allowing me to identify technological features that encourage continuous, long-term engagement with health tools.

These formative studies highlighted a significant challenge individuals face while managing their health. An overwhelming number of resources exist for cancer patients, and finding trusted tools to support one's specific needs is an extremely difficult task. I led the development of MyPath to reduce this burden. MyPath is a mobile application that integrates electronic health record data, online resources for patients, and patient input to present personalized health information to breast cancer patients. Interaction with and information from MyPath adapts as each patient progresses from diagnosis through treatment and post-treatment survivorship. An evaluation of patients' use of MyPath throughout treatment demonstrated the ability for personalized health tools to encourage health behaviors and influence patients' health beliefs.

My work addresses the following research questions:

1. What are the strengths and limitations of existing healthcare practices that help patients manage their health over time?
2. What are the key dimensions in a comprehensive, holistic view of cancer journeys from the patient perspective?



3. What are the critical design goals and technical features for a system that supports patients' health management over time?
4. What influence does a system that delivers personalized health information have on patients' health management practices and psychosocial wellbeing?

This work makes contributions to the Human-Centered Computing field through the design and evaluation of novel patient-facing tools and the assessment of adaptive interfaces within personal health tools. To the health informatics field, this work provides an approach to offering multifaceted support for patients and an evaluation of how such support impacts patients' health management behaviors.

# **CHAPTER 1**

## **INTRODUCTION**

A central goal of ubiquitous computing has been to extend people's abilities, allowing them to engage more directly into activities of learning and problem solving [7]. One way in which this goal has come to fruition has been through health informatics technologies. In particular, as mobile devices have become ingrained in daily life, and the sensing capabilities more robust, these devices have provided individuals with data and insights into their health behaviors with a level of granularity and regularity not previously available. With this data, people now have a new ability to actively participate in their healthcare. Mobile health (mhealth) interventions have used many strategies to help people engage in their health, including tracking health information, providing easier access to health information, and supporting patient-provider communication [8]. Evaluations of these strategies' influence on people's personal health management have been generally positive, demonstrating the ability for mhealth tools to support reflection, encourage behavior changes, and help individuals feel more in control of their health [9, 10].

Though advances in mobile tools for health management appear promising, the research field also faces significant challenges. One common challenge for ubiquitous computing has been creating systems that can account for the diversity between users, using information about the individual to tailor support [11, 7]. In healthcare, overcoming this challenge to offer more personalized support may have a significant impact on individuals' health and wellbeing. Patient centered care, a healthcare approach that respects and tailors care to the unique needs of each individual patient [12], is emerging as a seminal model in healthcare, listed as an essential component of quality care by the Institute of Medicine [13]. A number of studies have shown that this customized care correlates with improved health outcomes and quality of life [14, 15]. These results suggest that offering personalized health support

outside of healthcare settings may also lead to improved health and wellbeing, though advances in both the design and evaluation of personalized health tools are needed to verify this hypothesis.

The rise of chronic diseases worldwide is another motivation for more personalized support through health management technology. By 2020, over half of the adult population is expected to have at least one chronic disease [16]. A number of factors have lead to this change in healthcare, including an aging population and advances in medicine reducing the mortality rates of both acute and chronic illnesses [17]. This increase has placed great strain on the existing healthcare system. Care for chronic conditions requires more time than clinicians have available [18]. In response, healthcare is moving out of traditional clinical settings, and placing greater responsibility on patients' personal health management. Chronic disease management is a complicated process due to 1) the breadth of patient work required, 2) the changing needs of patients over time, and 3) the variety of factors that influence one's ability to effectively manage the disease, making the process different for each individual.

First, chronic disease management is particularly difficult for patients due to the breadth of tasks included in the process. A chronic illness affects far more than one's physical health. Individuals must cope with numerous physical and emotional challenges, balancing clinical tasks alongside the responsibilities of daily life [4, 19]. Designers and researchers can enhance the effectiveness of patient health tools by creating tools that address a broader range of the responsibilities and challenges that patients face when coping with cancer.

Second, patients' information needs change over time. Literature on illness trajectories has shown that individual cancer trajectories and information needs are extremely variable and continuously changing [20]. However, few mobile health systems today offer tailored support that considers these changes.

Finally, health management is a personal process that differs greatly between individuals. A patient's diagnosis, age, socioeconomic status, social support, and many other

factors can all influence one's ability to cope with the disease, and therefore alter their support needs [21]. Just as clinical practices have shifted to consider the diversity of patient experiences, so must the technologies designed to support their personal health management. For example, while one individual might benefit with sharing their health status on social media in order to receive support from friends and family members, another may wish to keep their health situation more private. Health technology should offer the flexibility to provide patients the autonomy to achieve these differing objectives.

A body of literature has grown within the field of Human-Computer Interaction (HCI) investigating how technologies can help patients manage these complex healthcare situations. Such tools provide and organize health information [22], help users reflect on their experiences [9], or foster social support [23], among other activities [24]. However, rarely do we find tools that possess the flexibility or robustness to cater to the full range of an individual patient's needs.

To overcome these gaps in technological support, I designed technology that offers personalized support to breast cancer patients from diagnosis through post-treatment survivorship and evaluate the influence of this technology on health behaviors and psychosocial metrics. I test the hypothesis: *flexible and adaptive mobile technology, informed by existing care practices and patient experiences, will help patients manage complex healthcare trajectories by motivating health management behaviors specific to one's individual needs.*

Through this research I advance our understanding of how we can create personalized tools to support complex healthcare illness trajectories. My research addresses the following research questions:

**1) What are the strengths and limitations of existing healthcare practices that help patients manage their health over time?** Health care practices have been increasingly focused on supporting more than patients' physical health. Cancer navigators offer one resource for providing personalized support to patients and reducing barriers to care. In chapter 4, I describe my formative work with cancer navigators, which outlines how existing

healthcare practices support patients' diverse and changing needs. I discuss opportunities for technology to support and amplify the personalized assistance that navigators offer to patients.

**2) What are the key dimensions in a comprehensive, holistic view of cancer journeys from the patient perspective?** A critical step in developing tools that offer patients comprehensive support is understanding the important and difficult aspects of cancer management from the patient's perspective. Using focus groups with a visual narrative exercise, I elicited input from breast cancer survivors about the significant moments that occur following a cancer diagnosis. In chapter 5, I discuss the results of this work, which lead to the development of a cancer journey framework that details how patient responsibilities and challenges change across common phases of care.

**3) What are the critical design goals and technical features for a system that supports patients' health management over time?** I developed a technology probe, called MyJourney Compass, to evaluate how cancer patients engage with flexible, mobile technology throughout treatment and survivorship to meet their personal and health needs. In chapter 6, I describe three analyses of the MyJourney Compass deployment data, including a qualitative investigation of the technology adoption and initial uses, an analysis of usage logs to identify patterns of use, and a comparison of usage logs and treatment plans to better understand gaps in use. Each of these evaluations reveal the strength and weaknesses of using mobile, customizable platforms to support personal health management, and offers implications for the design of personal health technologies. In chapter 7, I describe how I incorporated these design implications into the development of MyPath, a personalized and adaptive health information aid for breast cancer patients.

**4) What influence does a system that delivers personalized health information have on patients' health management practices and psychosocial wellbeing?** In my second field deployment, I assessed how personalized and adaptive health information influences patients' health management practices. In chapter 7 I describe the design of MyPath, a

mobile application that connect patients to personalized and adaptive health information from trusted websites recommended by our oncology partners. In chapter 8 I describe the MyPath field study. Using interviews with participants who received the MyPath application, I demonstrate how the application lead to more consistent engagement with the health content than seen in the MyJourney Compass study. This engagement allowed the MyPath content to positively influence participants' health management behaviors in a number of ways.

In short, I have run a series of studies with healthcare providers and cancer survivors to understand existing cancer care practices, as well as two field deployments to examine how novel mobile applications can support patient work within the actual context of use. Table 1.1 provides an overview of the studies, including the methods used, participant details, and corresponding research question(s). Few tools today capture dynamic patient journeys from the patient's vantage point. This work makes the following contributions to the fields of HCI and health informatics:

- A set of methods that modify commonly used qualitative methods to analyze change in healthcare experiences and practices over time (Chapter 3).
- Guidelines for developing technology that is informed by existing patient navigation practices (Chapter 4).
- A comprehensive framework of the breast cancer journey from the patient perspective (Chapter 5).
- The design and evaluation of MyJourney Compass: a tablet system that provides flexible and comprehensive support to breast cancer patients (Chapter 6).
- The design and evaluation of MyPath: a novel application that provides personalized and adaptive health information to users managing cancer (Chapter 7).

Table 1.1: Overview of dissertation research questions, methods, and participants

Research Question	Method	Participants
What are the strengths and limitations of existing health-care practices that help patients manage their health over time?	Thematic analysis of interviews with cancer navigators about work practices	7 cancer navigation employees
	Card sorting activity and surveys about health information sharing preferences	21 breast cancer survivors 3 doctors 2 navigators
What are the key dimensions in a comprehensive, holistic view of cancer journeys from the patient perspective?	Focus groups with visual narrative activity	31 breast cancer survivors
What are the critical design goals and technical features for a system that supports patients' health management over time?	Year-long MyJourney Compass field study, thematic analysis of participant interviews, analysis of usage logs, comparison of usage logs to EHR data	36 breast cancer patients
What influence does a system that delivers personalized health information have on patients' health management practices and psychosocial wellbeing?	MyPath field study, thematic analysis of participant interviews	8 breast cancer patients

## 1.1 Healthcare setting

All research described in this dissertation took place in Rome, GA in collaboration with the Harbin Cancer Clinic and the Rome Cancer Navigators. Rome, GA is a rural city in northwest Georgia, with a population of approximately 36,000 in the city and 95,000 in the general metro area <sup>1</sup>. The median income in the Rome area is \$34,000, and approximately one third of the population is below the poverty line. The population is 59.2% white and 28% African American<sup>2</sup>, and 16.3% of Hispanic origin<sup>3</sup>. Harbin and the Rome cancer navigators do serve a geographic area that spans beyond Rome, covering over 500 square miles, with patients from Georgia, northeast Alabama, and southwest Tennessee.

Harbin is a medical oncology center in Rome, Georgia accredited by the American College of Radiology, and a member of the Georgia CORE Research Network . The clinic includes 8 physicians and focuses on providing support to patients throughout the entire cancer journey. This holistic care includes prevention, detection, diagnosis, education, treatments, integrative therapies, and survivorship. Annually, they treat approximately 900 patients, 37% of whom are diagnosed with breast cancer.

The Rome Cancer Navigators is a nonprofit organization, developed in 2008, that provides counseling and assistance to patients with any form of cancer. Cancer navigators provide one-on-one support for patients from the time they are diagnosed with cancer until they complete their treatment. Navigators attempt to ensure that nothing impedes a person's ability to obtain medical treatment by helping patients receive an often customized set of resources including counseling, social security benefits, medical insurance, gas money, answers to medical questions and many other crucial resources. The Rome Cancer Navigators include two types of navigation: nurse navigation and service navigation. Nurse navigators primarily work on educating patients about their disease and answering medical questions. Both of the nurse navigators in this organization were registered nurses prior to joining the

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<sup>1</sup>United States Census Bureau Quick Facts

<sup>2</sup>United States Census Bureau, American Community Survey 5-Year Estimates: B02001, Race

<sup>3</sup>United States Census Bureau, American Community Survey 5-Year Estimates: B03001, Hispanic Origin



cancer navigation organization. Service navigators focus their expertise on understanding the resources available to patients, identifying patients' needs, and helping patients apply for resources for which they are eligible. Prior to joining the navigation organization in Rome, the service navigators in this organization both had careers in social work. I provide a more detailed description of this organizations' structure and work practices in chapter 4.

## **1.2 Dissertation overview**

This dissertation is organized as follows:

In Chapter 2, I describe related work that provides a background for my research. My work is motivated primarily by research related to illness trajectories, barriers to care, and mobile health interventions. I present research from each of these communities and briefly state how my research expands on these bodies of knowledge.

In Chapter 3, I present the methods I have used throughout my dissertation research, particularly for the studies described in chapters 4-6. Each of the methods I have used modify existing qualitative research methods in order to focus more directly on changes over time. While I unpack the details of each method in subsequent chapters, I provide an overview of each method and the strengths and weaknesses of these methods in practice.

In Chapter 4, I describe two formative studies I ran with cancer navigators and healthcare providers to understand how healthcare professionals support cancer patients over time, as they progress through the cancer trajectory. First, I present a qualitative interview-based study I ran with cancer navigators to understand their work practices. I then describe a study that involved cancer survivors, cancer navigators, and oncologists in an exercise that combined card sorting and surveys to evaluate key stakeholders' health information sharing preferences.

In Chapter 5, I describe my research with cancer survivors that led to the development of a comprehensive cancer journey framework. In this study I used focus groups and a visual narrative activity to study how cancer survivors reflect on their health experiences

and support needs.

In Chapter 6, I describe the MyJourney Compass study, the first of two field deployments. I developed the MyJourney Compass system as a mobile, tablet-based health management tool to study how patients would use mobile technology throughout the cancer journey, including diagnosis, treatment, and survivorship. The study explores the benefits and limitations of using flexibility and customization as design features within health tools.

In Chapter 7, I describe the design of MyPath, an application that connects patients to personalized and adaptive online health information recommendations. The design of this system was guided by the study results presented in chapters 4-6. I also present the usability evaluation I ran with healthcare professionals and cancer survivors.

In Chapter 8, I describe the evaluation of the MyPath system. This study includes a description of the broader randomized controlled trial that is currently ongoing, as well as a qualitative evaluation of patients' use of the MyPath application. The results of the qualitative study have demonstrated that patients' use of the application led to direct changes in their health management behaviors.

In Chapter 9, I reflect on this research. I describe what I have learned about using personalization as a technique to support cancer patients and reduce barriers to care. I also discuss the potential generalizability of these results, the impacts my research had on the existing healthcare system, and opportunities for future work. I conclude with Chapter 10, reviewing the important results and contributions that emerged through this research.

## **CHAPTER 2**

### **RELATED WORK**

#### **2.1 The cancer trajectory and patient work**

Considering patients changing health management needs is not a new idea. The term ‘illness trajectory’ has been used as a way of encompassing changes in the illness progression as well as the work required to manage the illness [5, 25]. Researchers have developed a body of literature detailing various aspects of illness trajectories, highlighting the complex tasks placed on patients in order to manage their health and wellbeing. For example, Corbin and Strauss identified three types of work that characterize the illness trajectory, including illness work, everyday life work, and biographical work, which involves restructuring ones life to accommodate new tasks and treatments [26]. Other work detailing patient tasks highlight the complex responsibilities placed on patients, such as obtaining information about their health situation, managing care across multiple physicians, and coping with new experiences and problems- tasks which are often overlooked by the healthcare industry [19, 2].

Other studies of patients experiences provide more in depth frameworks detailing patients experiences with disease management. One such project utilized an 18-week cultural immersion within cancer treatment centers to identify common phases within the cancer journey, such as diagnosis, information seeking, and acute care [27]. The study demonstrates how patients needs and goals drastically change over time, as a patient moves through these phases, their needs change along with the challenges they face. The first two phases occur during and immediately following the cancer diagnosis and include “rapid and aggressive searching for information (p.268).” In these early phases of the cancer journey many patients face increased stress and uncertainty [28]. These emotions can act as

a barrier against the patients engaging in information seeking activities, as the amount of information can feel overwhelming and unmanageable, hindering overall information seeking effectiveness [29].

During acute care and treatment the need for health information management continues. Patients must balance appointments with multiple providers, cope with various side effects, receive little time to speak with oncologists, and struggle to obtain details about their health status [27]. Upon completing treatment, breast cancer patients will often either show no evidence of the disease or, when that is not possible, will move into chronic disease management. During this time, quality of life becomes the emphasis, with patients often focusing on health promotion and coping with lasting emotional challenges [30]. In examining the cancer journey, we can see that breast cancer patients have a range of fluctuating needs, a subset of which we discussed here.

These works studying illness trajectories provide critical insights for understanding and supporting chronic diseases. However, with the rapid pervasiveness of technology in daily life, more work is needed to identify how patients manage their health in this environment, and how technologies may better assist this patient work. This dissertation helps to fill this gap, identifying technology features that encourage patients to use health tools throughout the cancer journey, and evaluating how use of novel health tools support patients' changing health management needs and tasks.

## **2.2 Barriers to care**

As patients take on the many tasks included within patient work, they face many physical, emotional, socioeconomic, and informational challenges that can impede on their ability to effectively manage their health. From the time of diagnosis, patients often face dramatic changes in their physical well-being [28]. Patients experience many side effects that result from their treatment including fatigue, nausea, and pain, and have little knowledge on how to cope with them [30]. In addition to these side effects, emotional distress, fear, and

feelings of loneliness impact patients quality of life [31, 32] Socioeconomic barriers are also numerous, including lack of insurance, issues organizing transportation to treatments, and other financial worries [21].

These barriers both impede on patients ability to access quality care, as well as their ability to manage and use health information resources designed to support health management while away from the healthcare setting [29]. In several studies the majority of patients have indicated a desire for more information [30, 33, 34]. Access to health information is difficult for several reasons. First, the information needs differ from person to person [33, 34]. Second, many people rely on healthcare professionals to provide information necessary to effectively manage their illness [35]. However, studies with breast cancer patients have shown that while health providers are the preferred information source, patients are often dissatisfied with the information they receive from their providers. Often this dissatisfaction is due to a lack of information and a lack of time to discuss relevant information or ask questions [36]. Information becomes even less accessible after completing treatment, despite persistent information needs about ongoing physical and psychosocial symptoms [31, 34].

The challenges triggered by a breast cancer diagnosis are typically compounded when patients are ethnic minorities or of a low socioeconomic status. Issues such as lack of insurance, lack of transportation, and language barriers are prevalent within these groups [2].

In my research, I expand on our understanding of health management barriers through the creation of a framework that outlines common challenges from the patients' perspective, and details how these challenges change as patients progress through the common phases of the cancer journey. Further, through the MyJourney Compass and MyPath field studies, I demonstrate the ability for mobile technology to reduce health management challenges by connecting patients to trusted health information.

## **2.3 Strategies for supporting patients' health management and reducing barriers to care**

Supporting patient work, and reducing barriers to care, can have important impacts on patients' overall quality of life and psychosocial wellbeing. Increased access to health information can lead to improved coping skills [37], less anxiety [38], and higher psychosocial wellbeing [3]. More informed patients also benefit the broader healthcare system by reducing emergency department visits and therefore overall healthcare costs [39].

### 2.3.1 Self-management programs

Regardless of the specific challenges one faces in their own personal health management, a common requisite exists for patients to become active partners in their care. For patients, taking on this active role is an important step in improving health outcomes [40]. Therefore, a great deal of effort has been put into helping patients take on this role as a partner in their own healthcare. Many approaches for teaching self-management behaviors have used in-person tutoring with doctors, nurses or other specialists [41]. Such tutoring can provide patients with information about their specific illness, teach patients how to monitor and manage common symptoms, offer recommendations for lifestyle changes, and provide additional emotional support. A significant benefit of self-management programs is their ability to improve patients self-efficacy [42]. Banduras theory of self-efficacy posits that ones belief in their ability to perform a behavior to produce the intended outcome influences the probability of actualizing that behavior[43]. Self-efficacy is widely considered a critical component of coping, and has been linked to self-management behaviors and improved quality of life [44, 45]. While promising, in-person self-management programs face several limitations. First, these programs are run by health professionals, making them costly and adding to the time constraints placed on these professionals [41]. Further, most studies involving self-management programs last only a few months, with no features in

place to offer longer term support or follow ups.

Mobile, ubiquitous technologies may offer the continuous engagement needed to overcome the limitations of these in-person programs. The National Cancer Institute has called for health technology that supports many of the same objectives as in-person self-management programs, including teaching coping skills, helping patients deal with the emotional ramifications of the disease, and providing information to help navigate the healthcare system and treatments [46]. The call also highlights that such technology ought to be personalized and fit easily into people's lives. However little guidance exists for how technology may incorporate this range of goals. The designs of MyJourney Compass and MyPath provide two models for offering patients with personalized and flexible health tools.

### 2.3.2 Cancer navigation

Another strategy to help patients overcome health management challenges has been cancer navigation programs. Cancer navigators typically provide one-on-one support for patients from the time they are diagnosed with cancer until they complete their treatment [47]. Navigators attempt to ensure that nothing impedes a person's ability to obtain medical treatment by helping patients receive an often customized set of resources including counseling, social security benefits, medical insurance, gas money, answers to medical questions and many other crucial resources.

In 1990, Dr. Harold Freeman developed cancer navigation (also called patient navigation) to address the severe disparity in healthcare delivery in the United States, with people at lower socio-economic levels facing higher cancer incidence and lower survival rates [48, 49]. At that time, only 38% of operable breast cancer patients in Harlem survived for five years, and 25% of the breast cancer patients that came to the hospital were inoperable due to the cancer being too advanced [50]. The goal of the initial program developed by Freeman was to improve the survival rate of patients diagnosed with breast cancer by using trained community health workers to help patients receive the care they

need. These health workers helped patients identify and overcome barriers that hindered their ability to successfully interact with the healthcare system. Over a six-year period, this program correlated to a substantial improvement in 5-year survival rates for breast cancer patients increasing the rates from 39% to 70% [51].

The goals of cancer navigation programs have since progressed. Navigation originally focused only on providing patients with access to cancer screenings and medical treatment but now includes a growing focus on patient experience and improving perceived quality of life. As a result, cancer navigation organizations have increased their ability to provide services related to psychosocial support and quality of life outcomes [52].

While all cancer navigation organizations work to eliminate barriers faced by cancer patients, there is currently no standardized approach to providing this care across the various cancer navigation organizations nationwide. Cancer navigation remains highly localized, which has the benefit of enabling the organizations to provide the cultural sensitivity and understanding necessary to meet the unique needs of their neighborhoods and patients [53].

In my research, I provide an analysis of how cancer navigation, as a sociotechnical system, support patient needs over time. I use the results of this work to inform mobile health tools that offer complementary support for patients. These tools extend the availability of personalized support that navigators offer, as navigators face significant time and resource constraints. I discuss these constraints further in chapter 3. Further, my research provides a model for partnering with cancer navigators in field deployments. In chapter 9 I discuss how this partnership benefits the research, the navigation organization, and the patients who participate in the research.

## **2.4 Mobile health interventions**

Mobile, ubiquitous technologies may offer the continuous engagement needed to overcome the limitations of the in-person programs described above. In the past decade we have seen a rise in the adoption of mobile tools across all ages [54, 55]. The pervasiveness of mobile



technology make it well suited to support patient needs when they are away from medical centers.

The HCI and health informatics communities have made several advances in understanding how technology can support patients illness management. Such tools help patients to organize health information [22], manage their healthcare when away from home [10], reflect on their experiences [9], engage with their healthcare team [56, 57], or foster social support [23].

Research evaluating the impact of mobile health tools offer promising results. For example, a clinical trial of an interactive assessment tool for leukemia and lymphoma patients, designed to help patients prepare for doctor appointments and deployed on tablet devices, indicated that the intervention correlated with a decrease in symptom distress [58]. the HealthWeaver system supported a range of cancer management tasks including tracking appointments, taking notes and monitoring symptoms. Use of technology was associated with an increased confidence in patients ability to control their health information [10]. A study of the ASyMS system, which tracked chemotherapy-related symptoms, revealed that the group that received the technology experienced less fatigue [59].

While promising, one limitation of existing tools for patients is that the technology typically focuses on supporting a specific goal or task. A review of mobile-phone health interventions outlined common mhealth strategies [8]. Some of these strategies, such as remote coaching, offer the flexibility to adapt to individuals changing needs. However, many of the strategies used by mhealth devices focus on particular health goals, such as symptom monitoring and exercise tracking, placing the burden on patients to integrate information from disconnected sources and repeatedly find and incorporate new resources as their needs and health management work changes. Few patient tools today consider the changing needs and goals of the individual, despite that disease management is a constantly evolving process, with individuals needs, goals and priorities changing over time. Within the HCI community, designers of health tools have called for the need to incorporate more

holistic support within modern patient health tools [60]. Thus, there is a need for technologies to offer the flexibility and robustness to conform to individuals evolving health situations.

### **CHAPTER 3**

#### **METHODS FOR STUDYING ILLNESS TRAJECTORIES**

A significant barrier to work understanding and supporting chronic disease management is the absence of research methods that consider time as a key construct in understanding how individuals' health management change over time. Common methods in user centered design work, such as interviews, focus groups, and technology probes, can offer useful insights into patient work practices and provide evidence for future tech systems designs [61, 62]. However, a limitation of these methods is that they do not focus specifically on change over time as a central component of patient work. A review of the literature provided little if any guidance for researchers to study changes over time, or to design systems to support individuals' changing health management needs or practices. Chronic disease management is an important context in which to consider how we may understand and support change, due to the many transitions individuals may undergo throughout illness trajectories [26].

To better support complex healthcare practices, Pratt et al. have discussed the importance of using ethnographic, qualitative methods to develop a rich understanding of the complexities within the healthcare setting [63]. The same level of rigor is needed to understand and support patient work over time. When reviewing research that specifically evaluates how processes change over time, I found that these studies typically rely on longitudinal methods that require arduous data collection across many months or years [64, 27]. Such resource intensive methods are often infeasible for researchers.

To overcome this gap in methods focused on the temporal components of health processes, I present an approach for assessing how the work involved in health management changes over time. My research follows a user-centered design process, analyzing existing healthcare processes and patient experiences in order to guide the design of a novel mhealth

system. The methodological approach I present helps to evaluate three aspects of disease management, and three of my primary research questions in this thesis:

1. How does the existing healthcare system support patients' changing health situation over time?
2. What are the key dimensions of disease management and patient work from the patient's perspective?
3. What are the strengths and limitations of using technological support for patients as they progress through treatment?

Respectively, the methods I used to assess these questions include repeated semi-structured interviews, visual narratives with focus groups, and longitudinal technology probes. Each of these methods builds upon a common method used in user-centered design. I provide the details of these modifications and discuss how they are useful for understanding the temporal characteristics of health management, as well as their limitations.

In this chapter I outline the three methods I used to study healthcare practices, patient experiences, and technological support, detailing the data collection and analysis we used in each method. I then share some of the significant findings from these three methods, both to demonstrate the potential contributions of these methods and to share results that I believe are important insights for future personal health management tools. Finally, I discuss the strengths and weakness of these methods, so that researchers who may wish to implement these methods in the future may use the lessons I learned throughout my own experiences.

While this chapter presents an overview of my work, I focus primarily on the strengths and limitations of the methods. A more detailed description of my study results can be found in Chapters 4-6.

### **3.1 Analyzing the healthcare ecosystem: Using a repeated qualitative assessment to reveal how healthcare practices manage patients' dynamic health situations**

While much of patients' disease management takes place away from medical centers, health management is a process that is integrated within a healthcare system. The broader system

in which an individual receives clinical care directly influences their disease management needs, goals, and practices. Patients rely on healthcare professionals for support and guidance, and doctors are the most common source that patients turn to for trusted information or when questions arise [65]. Thus, I believed a rigorous evaluation of patients' healthcare system would be necessary to identify existing resources for patients and to inform the design of patient-centered tools. Further, working with healthcare professionals is useful for identifying current strategies for support patients' changing health situations. Therefore, this first study was driven by the question: *How does the existing healthcare system support breast cancer patients' changing health situation over time?*

### 3.1.1 Method details: Repeated semi-structured interviews with cancer navigators

Many different healthcare professionals may be helpful participants in studies examining how care for patients with a chronic disease changes over time. In my partnership with Harbin Clinic, I found that cancer navigators were one of the central organizations focused on helping patients navigate the cancer care process.

I concentrated on studying navigation practices, as the goals of cancer navigators were to support patients over time, as they progress from diagnosis to survivorship. This organizational agenda aligned closely with my research interests. Further, cancer navigators interact frequently with physicians and other health professionals involved in treatment. The cancer navigators were present at patients' first meeting with their oncologist, attended weekly meetings with the oncology team to discuss new cases, and frequently visited the chemotherapy and radiation centers to offer additional support to patients. Therefore, working with navigators allowed me to study their work practices while also gaining insight into the structure of the broader healthcare organization.

To analyze navigation work practices, and how they handle the changing needs of their patients, I used a semi-structured interview method. This method been recommended when studying complex and sensitive issues, as they allow for probing and clarifications through-

out the discussion with participants [66]. However, participants are often only interviewed once, providing a snapshot view of their experiences. Prior literature has therefore indicated that interviews may be unsuited for questions related to issues that change over time and suggests that spacing interviews out may be beneficial in this scenario [67]. Based on this recommendation, I used repeated semi-structured interviews as the primary method in the study of navigation practices.

During this interview study I met with each member of the navigation organization 2 to 4 times over a one-year period. Participants included: an executive director, an office manager, a social worker, two nurse navigators, and two service navigators. This structure allowed for easier participant recall of events, and allowed me to evaluate how navigation practices changed over time as they worked with new patients and as previous patients progressed through treatment.

The interviews all used same core set of questions, which were split into two parts. In the first part of the interview I focused on recent events and tasks. Asking questions about recent events allowed the navigators to give specific examples of their work practices and often led to discussions regarding other events or activities. The questions were also valuable in allowing me to understand how navigators prioritize their work and allocate their time. In the second half of the interview, I followed up on information from previous interviews. This structure allowed for easier participant recall of events, and allowed me to see how navigation practices changed over time as they worked with new patients and as previous patients progressed through treatment. My semi-structured interview guide can be found in table 3.1.1.

All interviews were audio recorded and transcribed prior to data analysis. Two members of the research team participated in the data collection and data analysis in order to reduce personal bias. We first structured data using common phases of the cancer journey, as outlined in prior literature [27] in order to assess how navigation work practices change as individuals move through care. I also used an iterative inductive analysis of the entire

Table 3.1: Semi-structured interview guide

**Part 1:** Recent events ( 30 minutes)

1. Describe a recent work day
2. What are your most common tasks/responsibilities?
3. What was a recent challenge you faced?
4. Tell me about your last appointment with a patient.
5. Tell me about the last time you met with a new patient.

**Part 2:** Follow up on previously discussed cases ( 30 minutes)

data set to iteratively identify themes around future mhealth opportunities. This analysis is frequently used in qualitative studies [68]. In the analysis, each researcher independently created themes. We then collectively compared themes, created a codebook of themes, and reviewed the transcriptions to validate the themes with greater context.

### 3.1.2 Selected Results

The qualitative study with the cancer navigators provided insight into the diversity of cancer experiences and the volume of unexpected challenges caused by such diverse experiences, thus requiring navigators to remain flexible and agile to support patients in their day-to-day lives. The navigators provided a number of examples demonstrating how support needs differ across individuals, based on the patient’s personal situation. Following a diagnosis, navigators could focus their support efforts on helping patients’ find financial support for transportation to treatment, connecting patients to support groups, or beginning counseling sessions to help them cope with the diagnosis. As one navigator shared, initial meetings with patients are highly variable: *You don’t ever know how a patient is going to handle something. You might speak with them 10-15 minutes or you could be caught up for 2 hours.*

Such variability leads to frequent, unexpected events. The navigators have therefore learned to adapt to unexpected events so that they may support patients to the best of their abilities. Such agility at times can lead to changing schedules. Navigators shared that

this was common when patients experienced severe side effects or health deterioration: *Yesterday [the other nurse navigators] was out of the office at 4 o'clock, got a call one of her patients was in the hospital in a panic mode, needed somebody here now. So I just dropped everything. I went there and I stayed with him until she got there.* Changes to patients' treatments or personal lives also require the navigators to continuously adapt. For example, the nurse navigator attends many patients' initial appointments when they begin a new treatment, as patients typically require emotional support during this transition and have many questions about what to expect during the new treatment. Thus, as patients' treatment plans change, navigators also adjust their schedules in order to be present.

These findings helped me to identify opportunities for technological support in cancer care. In particular, I found that being able to support a breadth of needs and goals as well as changing treatments is an important part of supporting patients' health management, as these can impede on patient's quality of life and ability to manage their health. However, few health tools today have been designed with the direct goal of supporting change or surprise. Therefore, this study highlighted an important gap in current health tools: providing the flexibility to accommodate the diversity of health experiences and for supporting unexpected moments.

### 3.1.3 Repeated interview: Strengths and limitations

In reflection, beginning my analysis with healthcare professionals and using a repeated interview study were very useful for better understanding cancer care experiences and available resources within our partnering healthcare system. One benefit of working with healthcare professionals is that researchers are able to learn about a breadth of illness experiences. In my interviews with navigators were able to discuss how factors such as stage of diagnosis, living situation, and socioeconomic status of a patient typically influence the care the organization provides to that individual.

The repeated interview structure was also useful in allowing me to focus discussions on



actual events and patients. By talking with navigators several times throughout a year, I was able to learn about many different cases and patients, without relying heavily on navigators' memory. The cancer navigators work with hundreds of patients every year. With so many ongoing cases, recall of prior work can be very difficult. I found in the interviews that questions focused on recent events encouraged the navigators to discuss specific examples and activities, which I could probe and follow up on in subsequent interviews. In contrast, questions that focused on their work practices more broadly were often answered vaguely and without concrete examples. The repeated interview process thus allows healthcare professionals to stay focused on recent activities while also allowing researchers to learn about a variety of care practices with different patients, and following the progression of care over time. This was particularly useful for identifying changes in patients' treatment paths and needs, and how navigators reconfigure their support based on these changes. While I interviewed navigators every few months, the method could easily be adapted to accommodate different schedules and timelines. I found that navigators worked with so many patients that interviews could have been equally beneficial with less time in between.

One potential limitation of this method is that the method may be difficult to scale. In this study, I focused research efforts on a single organization whose objectives paralleled my own. I found this work with cancer navigators sufficient, as they were a primary resource within the clinical setting offering patients continuous assistance over time. Further, they worked closely with other members of the cancer care system, including oncologists and case managers, and could therefore discuss the differing roles of these healthcare professionals as they relate to patient care. Other studies may need to involve a broader range of stakeholders depending on the research questions and organizational structure of the healthcare setting. In such a scenario, a repeated interview method would require a substantial amount of time and effort for the data collection and analysis. In order to overcome this limitation, I recommend working with healthcare professionals whose work practices align with the research goals. Working with healthcare professionals who work with others

in the healthcare system is also beneficial, as they can provide more details of the overarching healthcare system, in addition to specific work practices.

### **3.2 Understanding patient experiences: Using visual narratives to identify patients' changing information needs**

As discussed in the previous section, working with healthcare providers can reveal important information about how patients' illness trajectories change over time and the resources available to them. However, with a great deal of disease management taking place away from medical centers, working directly with the individuals managing a particular disease is necessary for understanding the responsibilities and challenges faced by patients. Therefore, this phase of research was driven by the question: *What are the key dimensions of disease management from the patients' perspective?*

#### 3.2.1 Method details: Visual narratives

Working with the primary user before designing the technology itself is a common practice in user-centered design. Many methods have been utilized to engage participants in the design of new systems, such as interviews [69], focus groups [70], and participatory design [71]. However, the limitations of these methods are similar to those described in the previous section. Often, the experiences shared by participants in these settings reveal a snapshot of experiences, biased by their most recent situations.

Unlike the work with cancer navigators, I believed a repeated interview format would be unsuitable for a study with cancer survivors. I was concerned that the interview format would overburden patients who were undergoing treatment. For cancer survivors who had completed treatment, I anticipated that little value would come from subsequent interviews as the primary topic was on past experiences. Therefore, in this context we opted to utilize a different method for encouraging reflection of individuals' cancer experiences through the use of a diagram activity in which participants were encouraged to visually describe

their health management experiences. This method was motivated by previous work that used diagram creation to help participants reflect on complex subjects [72, 73].

In this work with cancer survivors, I encouraged survivors to create visual descriptions of their lives during and after cancer treatment. I asked each participant to either write or draw their experiences beginning at the time of diagnosis, though several participants opted to begin with an earlier moment pertinent to their cancer experience. I expected that creating such a diagram could be an overwhelming experience without more focused guidelines. Therefore, I used seven categories to guide participants' illustrations. I asked participants to draw or write about significant moments related to medical care; family and friends; work and finance; moments of change; problems or challenges; emotional highs and lows; and anything else that characterized their journey. I selected these categories based on the previous interviews with cancer navigators. I included the categories in the activity as a way to elicit information about patients' experiences that extended beyond treatment and physical health, as we were interested in capturing a more holistic view of patients' experiences. The categories also helped serve as a reminder to participants of events that they may have not thought of initially. Most participants used these categories to construct a timeline of significant events that occurred in relation to their illness and treatment, as shown in figure 3.1. I provided each participant with a large sheet of paper and different colored pens and markers to easily differentiate between category representations.

I ran this study with 14 breast cancer survivors. Thirteen of the survivors were currently taking hormone therapy and had completed some combination of surgery, radiation, and/or chemotherapy within the past year. One of the survivors was beginning chemotherapy at the time of the focus group. I chose to work primarily with survivors who had recently completed treatment as they could reflect on how their experiences and information needs changed as they progressed from diagnosis to survivorship.

All of the diagram activities took place in a focus group setting with 2 researchers and 2 to 4 participants, though all participants were given the option to do individual interviews if

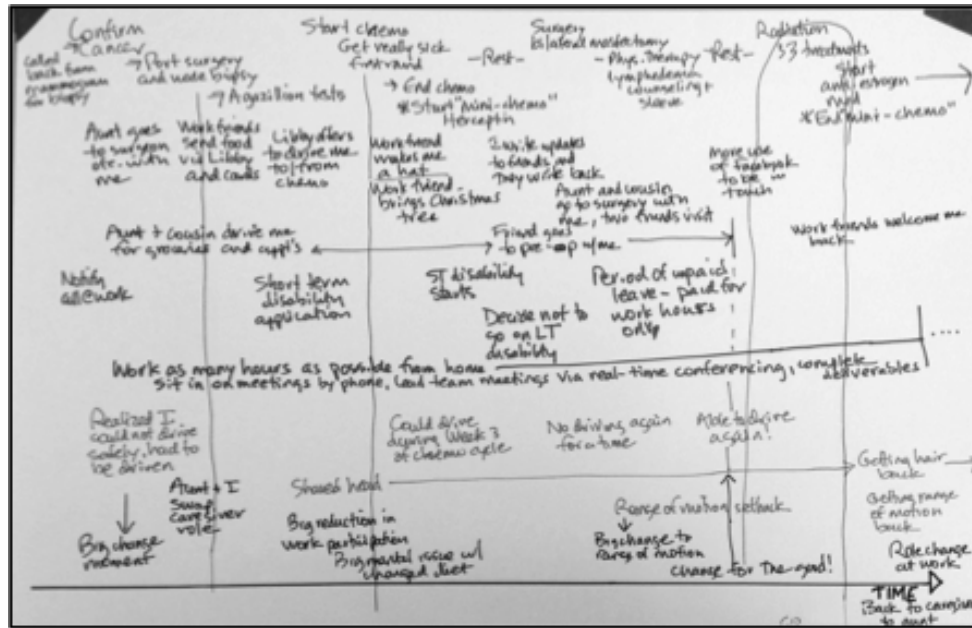


Figure 3.1: Sample cancer journey reconstruction

preferred. During the focus groups participants worked on their diagrams and then shared some of their reflections with the group. I recorded and transcribed all conversations. The final data set included transcriptions from each focus group and 14 cancer journey time-lines. I also copied and segmented the visual narratives, adding each individual event and associated category to the dataset for analysis.

To analyze this robust qualitative dataset, I had five researchers participate in an iterative thematic analysis. In this analysis process, each researcher independently reviewed the data and used open coding to develop themes. Researchers then met and collectively discussed and developed an agreed upon codebook containing high-level themes found in the data. In the second phase of analysis, the researchers again coded the dataset independently using the codebook. Finally, all researchers collaboratively compared their coding of the data and discussed discrepancies in order to reach a consensus. This helped to ensure that the final set of themes was comprehensive.

### 3.2.2 Selected Results

The diagram activity was critical in revealing the many challenges and responsibilities placed on patients at the time of diagnosis, and how they change over time. This data collection and analysis ultimately led me to create a cancer journey framework, described in chapter 5. The framework outlines the responsibilities, challenges, and personal changes individuals typically face upon diagnosis. In addition, the framework highlights how these responsibilities, challenges, and changes shift as an individual moves across common phases of care, including diagnosis, initial information seeking, acute care, and no evidence of the disease or chronic disease management. The results of this work directly influenced the design of MyPath, as I used the framework to create a comprehensive survey of patient challenges and needs that spanned beyond clinical concerns. I used this survey within the application to elicit structured user input and connect users to information that best suites their specific challenges.

One significant result that emerged from this activity was the number of changes patients grapple with during transitions of care. The responsibilities, challenges, and personal adjustments patients shared drastically differed as patients reflected on moments before, during and after treatment. For example, many participants focused on the need to make treatment decisions early in the journey and manage symptoms during treatment. However, after completing treatment, patients discussed new responsibilities, such as feeling a need to give back to the breast cancer community through volunteer opportunities and making more sustained health behavior changes.

The visual narratives also clearly demonstrated that the boundaries of the cancer journey from the patient perspective extend far beyond physical health and treatment side effects. I found that in reflecting on their illness experiences, many survivors included moments that were not directly related to their cancer diagnosis. For example, one participant wrote that a significant moment in her cancer experiences was *maintaining a 4.0 throughout studying for my BA in business*. Other participants wrote about personal responsibilities alongside

health tasks. For instance, one participant discussed the additional responsibilities placed on her after her husband passed away: *I was very busy dealing with the details following my husband's death. As executor of his will, I had many responsibilities.* While not directly related to the cancer diagnosis, managing daily life events alongside one's health can lead them to become interwoven into one's mental model of their health management activities. This finding further suggests the importance of allowing for flexibility in mhealth interventions, allowing individuals to combine health and personal work in ways that parallel their daily responsibilities.

### 3.2.3 Visual narratives: Strengths and limitations

While there are many possible methods for facilitating discussions about disease management with survivors, the visual narrative method offers three important benefits. First, the visual narrative activity, guided by the categories, gave survivors the scaffolding to creatively reflect on their experiences while considering past events from multiple perspectives, thus allowing us to understand both the breadth of their experiences and how changes occurred over time. Using the categories was particularly useful for this type of reflection, as it helped participants break down the complex concept of disease management into more specific questions. Also, because participants were working on one large diagram, they could easily go back to previous categories and add things as they arose. I saw several participants switch between categories later in the event when they remembered something they had previously left out.

Using focus groups also helped participants' recall of past events. I found that throughout the hour-long meeting participants would continuously converse with one another, sharing experiences with each other. By sharing memories together, participants would recall more experiences. An event discussed by one participant would serve as a reminder of events in their others' cancer care. I found that the combination of diagram categories and shared experiences with the other participants helped participants to consider a breadth of

events over the past year, including both good and challenging moments in care. These recollections allowed me to create a broad framework, highlighting a number of opportunities for technological support in patients' health management during cancer care.

One limitation of the visual narrative method is the accessibility of the activity. We had one participant who did not feel comfortable writing, thus limiting her ability and willingness to engage in the activity or with the group. In this situation, we opted to have one researcher work with the participant, writing on the diagram for her. Unfortunately, this meant she was less able to participate in conversations with other participants. Researchers who use this method or other methods involving writing should be aware of this limitation and plan alternative activities for participants who are not able or willing to read or write. Participants may also appreciate being told before the meeting about the method, so that they may opt out if they are uncomfortable, or choose to participate in an interview instead. Another possible solution is to involve caregivers who may be more comfortable writing for the participant, however this can introduce some bias into the data as caregivers will bring their own perceptions of events and experiences.

### **3.3 Assessing feasibility of technological support: Using technology probes to understand how patients assimilate technology throughout treatment and survivorship**

An important consideration when developing mhealth systems is whether individuals will be willing and able to use the technology in daily life. Many mhealth interventions use mobile phones. The pervasiveness of mobile phones helps to reduce many barriers to adoption, particularly if individuals may use their own devices. For interventions using other platforms, such as tablets or wearable devices, more research is needed regarding individuals' willingness to engage with the technology. In addition to the device itself, many health applications are already available to help people manage their health. Understanding the strengths and limitations of these existing resources is necessary for identifying how new mhealth systems can extend, rather than duplicate, the available support for pa-

tients. Therefore, my primary research question during this phase of research was: *What are the strengths and limitations of using technological support for patients as they progress through treatment?*

### 3.3.1 Method details: Technology probe

In my work with breast cancer patients I was interested in assessing patients' use of mobile tablet computers. Though less common than mobile phones, tablets are becoming increasingly popular among adults in the U.S. In 2015, approximately one third of adults in the U.S. over the age of 65 owned a tablet computer [54]. I believed this technology would be particularly beneficial for my older patient population as the larger screen allows for more accessibility features, such as larger text. Thus, an important research step was to assess the potential opportunities and limitations of using tablets to support breast cancer patients.

Technology probes involve studying a technology in the actual context of use in order to understand users' needs in the real world while also field testing the technology itself [74]. Technology probes are traditionally under-designed, allowing for participant adaptations to the system. Technology probes have been used frequently by researchers assessing health systems [75, 56, 76], though their timeframes typically span a few hours to several weeks. Since the previous study showed how patients' needs changed as they transitioned from diagnosis to treatment and survivorship, I required a technology probe that would allow me to assess use throughout the illness trajectory. Thus, I utilized a more longitudinal probe to study how patients would use tablets as a part of their health management during and after treatment.

To assess patients' use of tablet computers, I put together a suite of existing health resources to include on the devices during the technology probe study. I partnered with a team of oncologists, cancer navigators, and breast cancer survivors to select the resources to be included on the tablet devices. The team selected several mobile applications, PDF informational resources, and websites that were considered trustworthy and useful for breast



cancer patients. Applications and websites we added to the tablets included Caring Bridge, cancer.net, MyFitness Pal, and other health management applications. PDF information came from the cancer clinic, and included information about cancer treatments and side effects. We also included a few applications that were not health focused in order to encourage participants to use the devices as they would their own personal technologies. Such applications included Facebook, YouTube, and Angry Birds. In addition to these applications, participants were encouraged to add any content they wished to the tablets. This tablet system allowed me to assess how patients would use both the tablet devices and existing resources to support their health management.

During the yearlong deployment, every newly diagnosed breast cancer patient was invited to join the study. Participants received a Nexus 7 inch tablet with the selected suite of resources preloaded on the device. Participants also set up a training session to learn more about the included resources and how to use the device more generally. Participants were able to keep the tablets and could add their own content, such as email, calendars, and games. I did not provide any rules or restrictions on how participants used the tablet devices, thus encouraging participants to use the technology as they would use their own personal devices.

During the study I analyzed usage logs to capture participants' tablet use. In particular, each time an application was opened on a device I captured the application name, the date and time the application was opened, and the duration of use. Through the usage logs, I captured 40,884 distinct instances of application use, across 239 unique applications. To analyze the log data, I tagged each instance in which a health application added by the research team was used. I then aggregated daily use of each participant and mapped the usage over time. This allowed me to compare general tablet use over time to the use of health applications over time.

During the year I also interviewed participants after they had the tablet for at least one month. The combination of usage logs and qualitative data allowed me to understand

both how and why participants chose to engage with the technology. Further, adding a qualitative method provided user feedback not otherwise available in traditional usage log data.

### 3.3.2 Selected Results

36 participants enrolled in the study. By monitoring their usage of the tablets I identified a number of interesting ways that participants used the technology to support their health management. Participants used the tablets in a variety of ways. Common uses included recording questions for clinicians, looking up health information, and playing games during chemotherapy in order to stay calm. I describe these uses in greater detail in chapter 6. Discussions with participants also revealed that the mobility and privacy afforded by the tablets motivated participants' initial use of the technology. Privacy was particularly important to many of the participants, as they lived in a smaller town but did not wish to make their diagnosis public. Participants found the tablets to be less conspicuous than the common cancer documents all patients receive at the time of diagnosis, allowing them to look up health information in public locations.

As previously mentioned, technology probes are generally flexible systems in order to allow researchers to study how participants adjust the tool to fit their needs. Being able to add their own content onto the tablets proved to be an important feature for our participants. 35 of the 36 participants added content onto the device, including photos of family and friends, and applications such as Amazon Kindle and Bible related applications. Interviews with participants showed that such modifications helped to make the devices more personally meaningful, and therefore encouraged participants to keep the technology with them throughout the day, thus making health resources on the tablets easily accessible when needed. Surprisingly, participants were also able to use many of these applications, which typically would not be considered health tools, to meet their personal health goals. For example, one participant used YouTube to learn how to cook healthier, vegetarian meals.

Other participants used social media to share health updates with family members, and many participants used games during chemotherapy to help them stay calm during the stressful treatment.

A final interesting discovery was that many of the participants' tablet use (n=17) followed a similar pattern, characterized by bursts of health-related activity with gaps in use lasting between several days to two weeks. Further, I found that participants did most of their information seeking immediately following diagnosis, and less once treatment began. This results complements findings in other studies of patients' cancer experiences [27]. Discussions with participants helped to reveal why this pattern was so common. Many participants shared that they would take very purposeful breaks from thinking about their health, as they didn't always want to feel like a cancer patients. They therefore would take breaks from using the tablet devices, but would return to using them as new health concerns or questions arose. As one participant summarized, "I'm going to use [the tablet] more for other things than research on cancer stuff. Unless they say 'you have to do a new treatment', then I'll go and research that." Such insights are important for the design of future health tools, as it suggests that notifications from health management applications should be limited, respecting patients' desire for 'breaks' from focusing on their health situation. These results also point to an interesting opportunity for future technology that can anticipate users' needs and side effects, helping to make patient health management less reactive and more focused on preventative behaviors.

### 3.3.3 Technology probe: Strengths and limitations

The primary benefit of technology probe studies is that researchers can study user needs and behaviors in the actual context in which the technology would be used. Therefore, this type of study allows for identifying user needs that may not be apparent through other studies. In addition, technology probes allow researchers to analyze usage log data. Log data provides more objective insight into user behavior than participants' recollection of

their behaviors [77]. Log data can therefore yield results that would not emerge in other studies, and can help guide discussions with participants about their use of the technology.

When implementing technology probes, researchers must be very careful to respect and guard participants' privacy, particularly when collecting usage log data. Modern technologies can track a vast amount of user data. However, as more data is collected the study risks also increase. Researchers must consider the objective of the study to determine the minimal amount of data that needs to be captured. In my study, I opted not to collect any location information or application content, such as web searches or social media posts. While such data could provide more information about participants' use of the tablets, I found the data captured was sufficient for identifying design opportunities for future mhealth interventions.

### **3.4 Summary**

I believe there is an important opportunity to better understand and develop strategies for supporting patients' chronic disease management, with a specific focus on support changing needs over time. To close this gap, I first outlined three areas that are important for understanding the existing disease management context: the work of healthcare providers, the experiences of survivors, and the strengths and barriers of existing technology. For each of these areas of analysis we discussed a method we employed to examine change over time. Table 3.2 provides an overview of the methods I used and the strengths and limitations of each. I presented my own reflection of these methods in order to facilitate future research, particularly those interested in supporting individuals' dynamic health needs and goals.

Of course, the methods I discussed are not a comprehensive list of the many methods that could be used in the analysis of healthcare systems. However, this approach does offer some key benefits. First, these methods focus on reflection from various stakeholders in the healthcare system without relying greatly on participant recall, or by supporting re-

Table 3.2: Summary of research questions, methods, strengths and limitations

<b>Research Question</b>	<b>Method</b>	<b>Strengths</b>	<b>Limitations</b>
How does the existing healthcare system support patients' changing health situation over time?	Repeated Interviews	Can study how illness trajectories differ across patient population; Allows researchers to follow individual patient cases over time; Can discuss many cases without relying heavily on participant recall	Time required for data collection may make it difficult to scale for large healthcare teams
What are the key dimensions of disease management from the patient's perspective?	Visual Narratives	Facilitates reflection of a complex concept using an engaging activity; Focus group setting provides supportive environment for survivors to share and recall events; Diagrams reveal scope of disease management from survivors perspective	Accessibility: need alternative method for participants not able to or comfortable with writing
What are the strengths and limitations of using technological support for patients as they progress through treatment?	Longitudinal Technology Probe	Allows study of users' needs in actual context of use; Analysis of log data provides objective insight into technology uses	Increased data granularity leads to an increase in privacy concerns and data security risks

call through various mechanisms. Second, these methods help to reveal the comprehensive support needs of patients. For example, in my research I found that cancer navigators focused on supporting barriers to care, including logistical and financial challenges. Further, cancer survivors talked about their illness experiences broadly, highlighting both health management and personal responsibilities and milestones.

Finally, the methods I describe here are flexible, and may be easily altered by researchers. For example, each method may be used with different stakeholders. I expect that the visual narrative method, for instance, could be useful to engaging health providers in conversations about medical practices and organizational structures. Similarly, technology probes can be useful tools for studying medical devices or other technological systems in the clinical setting.

Incorporating methods that allow researchers to evaluate health management practices over time is a necessary step in developing information technologies that better support patient work throughout the entire illness trajectory. The methods I describe here offer one approach that allows for a focus on change over time, with less time and resources required than many longitudinal research projects. My hope is that these methods begin an important conversation in developing best practices for studying and designing for long-term health issues so that we may better support the millions of people around the world coping with these difficult illnesses.

## **CHAPTER 4**

### **EXISTING HEALTHCARE PRACTICES SUPPORTING THE CANCER JOURNEY**

In this chapter I present two studies assessing existing healthcare practices, evaluating the strategies health professionals use to support cancer patients over time. In the first study I worked with cancer navigators of Rome, GA to understand how they interacted with patients as they progressed from diagnosis to survivorship. In the second study I worked with navigators, clinicians, and patients to examine what information each of these stakeholders believe are important factors to share in order to collectively ensure that patients receive the necessary support from their health team.

These studies make the following contributions: 1. I introduce cancer navigation as a collaborative care network, and describe current navigation practices with a focus on communication and coordination techniques and technology usage. 2. I identify opportunities to support cancer navigation through future technological innovation and research, thus expanding the design opportunities for collaborative health technologies and patient health tools that complement these practices. 3. I examine the health information sharing preferences of patients, doctors, and cancer navigators across 23 distinct health factors relevant to the breast cancer journey. Results highlight the willingness of those involved in the cancer care process to utilize tools that encompass a robust set of health factors. 4. I reveal discrepancies between patients, doctors, and cancer navigators' health information sharing preferences. Misalignment was particularly evident in regards to sharing emotional health factors. The finding points to an opportunity for technologies to bridge the gap so that patient tracking behaviors align with the informational needs of their healthcare network.

## **4.1 Cancer navigation: Opportunities and challenges for facilitating the breast cancer journey**

In this section I describe the coordination and communication practices of cancer navigators, identify the role that technology plays in supporting navigation work, and uncover opportunities where technological support could improve cancer navigation. I describe the various roles and responsibilities present in a cancer navigation organization and map these tasks to common phases of the breast cancer journey [27]. I classify findings into five key categories: resource monitoring, knowledge transfer, case management, long term navigation, and the development of best practices. For each category I review cancer navigators' current strategies, identify challenges, and offer design opportunities. Through this work I offer new insight into how technical systems may support cancer navigation practices. Further, the results of this work provide strategies for patient health tools that offer complementary support.

### 4.1.1 Background

#### *Medical Care Coordination*

Many aspects make hospitals and healthcare centers complex adaptive systems. The intricacy of these socio-technical systems makes studying their cooperation and coordination methods interesting and important for enhancing medical practices. Previous research has examined many aspects of these systems. For example, research exploring healthcare coordination helped explain how health professionals collaboratively search for information [78] and how staff members communicate in emergency departments [79]. Researchers in this area have also studied how patients interact with information in clinical settings [80]. Further, research has shown how technologies can enhance various medical processes. For example, previous studies deployed and evaluated technology for operating suites in order to enhance surgery coordination [81]. This segment of healthcare research shows how en-



hanced coordination can improve medical practices. However, past research has primarily focused on examining healthcare systems comprised of patients, physicians, nurses, and pharmacists. In contrast to previous work, my work highlights the need for research that examines healthcare professionals who exist outside of the traditional areas of study, such as cancer navigators, since these professionals will become important stakeholders of future healthcare coordination technologies and significantly influence patients' healthcare experiences.

### *Cancer Navigation Research*

Limited work has been done to study cancer navigation. Most studies focus on providing a general definition and overview of navigation duties, as cancer navigation remains a new and evolving field for researchers [82]. Recent research looked at practices for developing lay navigation programs that recruit volunteers and cancer survivors as cancer navigators for newly diagnosed patients [83, 84, 85]. Understanding the cost effectiveness of cancer navigation programs is another area of interest that presents many challenges [86], as well as gauging patient satisfaction with navigation programs [87].

While all of this work helps to explore cancer navigation practices, there remain gaps in the research. To date, I am unaware of any investigation into the work practices of specific cancer navigation organizations in order to gain a deep understanding of its inner workings. Due to the highly localized nature of cancer navigation, concentrated case studies will help clarify the nuances of navigation work, while providing greater insight into the common strategies, challenges, and opportunities for support across navigation organizations.

Further, I am unaware of any research that has examined a cancer navigation organization as a socio-technical system. In order for HCI research to support navigation, we must gain a clearer insight into the interfaces and technological interactions that impact current navigation strategies. This research expands on the existing knowledge of cancer navigation by providing a focused study that begins to address these specified research gaps.

#### 4.1.2 Methods

In the investigation of cancer navigation, my goal was to understand the day-to-day routines of navigators and to explore the use of technology to support the navigation process. Over a six-month period I conducted 7 semi-structured interviews and 1 focus group session with the employees of the Rome Cancer Navigators, including the executive director, office manager, social worker, nurse navigators, and service navigators. My investigation focused on understanding navigation responsibilities, the navigators' primary challenges, and their technology usage. I transcribed the interviews and focus group for later data analysis. To analyze the data, I structured the data using two approaches. For the first approach I organized the data along the established cancer journey framework. Once I understood navigation practices as they relate to a general cancer treatment timeline, I focused on constructing a framework around future design opportunities. To surface the themes in the data I used an iterative inductive analysis to cluster segments from the transcripts and develop theme concepts. Members of the research team then verified each of the themes and reviewed the transcriptions for theme validation.

Throughout the course of this project I have also collected data from breast cancer survivors and oncologists working with the cancer navigators. These interviews allowed me to assess the completeness of my portrayal of cancer navigator work practices. Namely, I do not have additional data that points to unexplored areas in cancer navigation.

#### 4.1.3 Findings

##### *Mapping Navigation to the Breast Cancer Journey*

Understanding the steps a breast cancer patient must go through can be difficult as there are many different types of breast cancer, each with different treatment options available to a patient. Hayes et al. found that commonalities exist across individual cancer journeys, which can be described in five major phases: screening and diagnosis, initial information

seeking, acute care and treatment, no evidence of disease, and chronic disease and disease management [27]. In order to demonstrate the role of navigation throughout the breast cancer journey, I will explain how the navigation process changes through these phases (table 4.1.3 summarizes the responsibilities of the navigators at each phase). Though I attempt to categorize the process, cancer navigation is a flexible and dynamic activity that is tailored to each patient's individual needs and cancer journeys.

#### *Screening and Diagnosis*

The first phase of Hayes et al.'s cancer journey is Screening and Diagnosis. In breast cancer, the first step after an abnormal breast cancer screening result is often surgery. The goal of surgery is to remove as much of the cancer from the body as possible and to prevent the cancer from returning. Navigators attempt to make first contact with the patient at this point in the cancer journey.

The responsibility of making first contact with patients falls on the nurse navigators. Nurse navigators will meet with the newly diagnosed patients during their first meeting with the general surgeon. In this meeting the navigators focus on providing emotional and educational support. Nurse navigator N1 described the meeting as follows:

*"There's a lot of different focuses. [Answering] questions is one, to just reassure them that I'm there to support them, I become their shadow. That's what I tell them, 'I'm your shadow through all this. And just know I'm here to do whatever you need me to do. I can look up records; I can tell you what the doctor said. For instance, the patient gets home and everybody in the room forgot what was said, I can actually go online and read what the doctor said word for word. And then it's to reassure them that we have services that are here and readily available to them whenever they're ready and comfortable with coming here or talking to one of the [service navigators]."*

#### *Initial Information Seeking*

After completing surgery, breast cancer patients will often go through additional treatment including chemotherapy, radiation, or a combination of the two. According to the cancer

Table 4.1: Breakdown of Navigation Responsibilities by Breast Cancer Phase

Phase	Role	Responsibility
Screening and Diagnosis	Nurse Navigator	Meet with patients Introduce patients to navigation Answer medical questions Provide emotional and educational support
Initial Information Seeking	Nurse Navigator	Refer patients to service navigators Follow up with patients as needed to address medical/health questions
	Service Navigator	Meet with patients for initial needs assessment Help patients apply for necessary resources Provide emotional support
Acute Care and Treatment	Nurse Navigator	Provide support at health centers during treatment Answer medical questions that come up during treatment
	Service Navigator	Continue work from previous phase Refer patients to social worker for counseling if needed

navigators, there is often a three to four week gap between surgery and treatment. During this time a shift occurs where patients will meet less frequently with nurse navigators and more frequently with service navigators. Referrals usually trigger this shift, in which the nurse navigator provides the office manager with the name and contact information of patients requiring service navigation. The service navigators can then contact the patient to set up future meetings at the cancer navigation office. Similar transfers of patients between nurse and service navigators based on phase and needs is seen throughout the cancer journey, particularly when beginning the initial information seeking phase and the acute care and treatment phase.

With service navigators acting as the primary navigators in the initial information seeking phase, S1 described this time as the most important point for them to meet with patients:

*"A perfect patient, they know what's going to happen but they haven't started treatment yet. So by the time they start to get those resources, about a couple weeks in, it kind of gets*

*them over the hump.”*

The service navigators utilize numerous resources to provide aid to eligible patients. Based on a patient’s needs, these navigators help patients apply for and receive social security benefits, gas cards and other transportation assistance, assistance with rent, food stamps, cell phones to communicate with their providers, dental assistance, as well as Medicaid and other medical insurance benefits. If service navigators are able to meet with patients prior to the commencement of their chemotherapy or radiation, they are better able to help patients access these resources by the time treatment begins. This timeliness can be particularly important for patients whose ability to access treatment relies solely on accessing these resources. Radiation, for instance, usually requires patients to go to the health center every day for several weeks. For many patients, daily transportation to the health center would not be possible without gas cards or other travel assistance.

To determine which resources a patient requires, the first one-on-one meeting between a patient and service navigator focuses primarily on assessing needs, while also providing an opportunity for relationship building. The service navigators have developed their own resource checklist which they complete as they talk to the patient. This checklist includes all of the resources navigators know they have available as well as a rating scale that helps the navigators predict how much time they will need to spend to obtain the necessary resources for the patients. Both of the service navigators indicated relying heavily on these documents. S2 specifically stated:

*”[The checklist] gives us a guide and ensures that we are going to gauge everything that we know to gauge.”*

Another aspect of the one-on-one meeting is evaluating a patient’s social support and mental well-being. If needed, service navigators will refer patients to the social worker who works in the navigation organization, or they will provide patients with information about local support groups. All of the navigators discussed the importance of providing counseling for their patients. N2 discussed previous incidents that led to this understanding:

*"Some people have a lot of support, others have no one. That's been shocking. I thought that everybody had somebody in their life, a friend. And sometimes people get embarrassed and they'll say 'I have lots of friends, I don't need you'. And then when I go to the hospital after their surgery there's nobody there. And they'll say 'I lied to you.' "*

After completing the needs assessment, service navigators will work directly with patients to help them acquire their needed resources. The ultimate goal is to get the resources to the patients by the start of treatment so that no barriers impede the patient's ability to access the treatment they need. Securing aid for the patients in advance of their treatment allows the patients to focus on their health and not worry about whether or not they will actually be able to receive treatment. During the process of obtaining resources, navigators will put some of the responsibility on the patient, as described by S1:

*"Almost all of the time, we'll start the process but we want to make them finish it. You know like we'll say 'make this call, we're going to talk to them, we're going to tell them your story, but then we're going to hand you the phone'. Just to give them that autonomy and just to give them that responsibility as well. To make sure we're not just doing it for them. It also just gives them that empowerment, I think, because you know they have a problem that's bigger than they are, and then if we give them the tools to do it, they've fought that problem. And so to me it's just a good way to give them back some control."*

#### *Acute Care and Treatment*

As patients begin their post-surgery medical treatment, the emphasis returns to the nurse navigators. During treatment, nurse navigators often meet patients at the health centers where their treatment takes place to provide an added level of emotional support. In addition, nurse navigators continue to provide education to patients by answering medical questions as they arise throughout the treatment. As patients begin to experience various side effects, this support becomes particularly significant. N2 described the importance of being available to answer these medical questions for patients' emotional stability:

*"Chemo nurses are really busy If someone's panicked you don't want to be called back*

*at the end of the day, and you don't want to go to the emergency room. A lot of things that people freak out about is a common side effect. So we try to nip that and that way they are at peace."*

Also throughout this phase, service navigators will continue to help a patient apply for available resources if the applications could not be completed prior to treatment. The role of the service navigator then begins to shift towards providing the level of emotional support desired by the patient. Patients may indicate this desire by visiting the cancer navigation office or calling their service navigator. At this point, maintaining continuous communication with navigators is the responsibility of the patient. However, if a navigator determined in the needs assessment that a patient required counseling from the social worker, the social worker will organize counseling sessions during this phase, although the time period will change based on individual needs.

#### *No Evidence of Disease/Chronic Disease Management*

As patients move forward in their breast cancer journey, their relationship with the navigation organization can vary. Some patients will stay in close contact and come in to the navigation office frequently while others do not. All charts and files created by the navigators are saved if needed for later reference. As patients go through treatment, the service and nurse navigators will often follow up with them to ensure their care is continuing as expected. N1 detailed how she follows up with patients:

*"When I get a free day, what I try to do with those is just sit down and call and say 'hey, just wanted to see how you're doing, how's your treatment going' and just follow up. And it may take me several days to do that, just pulling a handful of charts at a time, but I try to follow up with them as much as I can."*

#### 4.1.4 Design opportunities

Understanding navigation practices, described above, provides useful insights into how technology can provide complementary personalized care to patients. These results have

informed the design of the MyJourney Compass and MyPath systems (as described in chapters 6 and 7). This work with the cancer navigators also pointed to other opportunities to directly support cancer navigation practices. In this section, I describe these opportunities, as they highlight important areas for future research.

In examining cancer navigators' daily workloads, I found that the majority of their responsibilities revolve around five central themes: resource monitoring, knowledge transfer, case management, long term navigation, and development of best practices. For each of these themes I discuss the strategies developed by the navigators to handle the workload, current challenges, and design implications that may help direct future research in the cancer navigation space.

### *Resource Monitoring*

#### *Current Strategies*

Resource tracking is an important and continuous task for the service navigators. Financial institutions such as foundations continuously open and close due to the availability of funds. This fluctuation causes navigators to constantly search for new resources. To find resources and track their availability over time, navigators use basic search engines. Both service navigators mentioned using Google frequently to look up possible resources for patients. S1 discussed with us how communication between navigators helps promote efficient searching and reduces the potential for overlapping efforts:

*"We communicate really well together, like, if I go and I get somebody's rent paid I immediately tell [the other service navigator]. Or if she gets somebody's power bill paid then I know about it. So then that way we know, 1) that it worked and 2) just to be careful with it. You know, because we don't want to drain them. And so it's really, there's not an official way of doing it, we just kind of talk it out and tell each other."*

#### *Challenges*

One of the biggest challenges facing navigators is the decline of money and resources



available to patients. As N2 described:

*"The resources started drying up as the economy, so we didn't have as much to offer."*

The distribution of limited resources is an obstacle that navigators address up front through the needs assessment. They work to ensure they do not over-utilize limited resources so that high needs patients are able to access the resources. As S1 discusses, ensuring the availability of resources for those who really need them is not only important for the patients, but for the organization's reputation as well:

*"We really like to keep our resources kind of close to the chest because we don't want other people to take advantage of them. And then we can kind of do an internal process of screening. You know, like if we know a certain association will pay rent, we don't want to refer everybody that comes through that says 'oh, I need my rent paid'. We don't want to refer them because we know those funds will go out and then they'll stop seeing us as a viable referring agency. So we kind of do our own little screening process."*

Resources also tend to be limited to patients beginning treatment. Patients who do not inform navigators of their needs early in the process often do not receive needed aid. This lack of flexibility in the aid distribution process inhibits navigators' abilities to assist high needs patients who are at later points in the cancer journey. S1 opened up about recently trying to deal with this issue.

*"That patient I was telling you that came in yesterday, his last radiation treatment is today, and they came in yesterday. And I know they were struggling. They're a \$700 a month income with seven people in the house. And it was hard because it's like I could have gotten you at least \$100, but now we're going to have to see if we can even get that."*

#### *Design Implications*

An intrinsic conflict exists when it comes to collaboration across cancer navigation organizations. Sharing strategies, resources, and services may be key to developing a collective practice that currently does not exist in cancer navigation. Such a collective practice could help in growing existing organizations, providing a larger variety of services to patients in

any particular community, and help in building new navigation organizations in communities that do not yet have them.

The decline of available resources, and the risk of depleting available resources further, hinders the development of such a collective practice. If navigators were to share their resources with organizations across the nation they risk not being able to provide for their own patients should the resource become exhausted.

This conflict indicates a direct need for researchers to explore ways in which cooperation can be promoted amongst navigation organizations that enhance the collective navigation practice and best supports the needs of individual patients and communities. For example, tools which allow navigators across organizations to share search strategies or rank resource providers may prove beneficial. Technologies such as these will allow navigators to find resources more efficiently without the fear of losing specific resources.

### *Resource Monitoring*

#### *Current Strategies*

Throughout any given day, cancer navigators are continuously interacting with providers, patients and with each other. Communication with providers in the community we investigated is particularly crucial for the nurse navigators, who rely on the doctor's schedules to determine when new patients are being diagnosed. Some technological solutions begin to support this collaboration. Nurse navigators received access to doctors' calendars and patients' electronic medical records and have included reviewing these sources as part of their daily routine. While the nurse navigators no longer need to wait for clinical nurses to fax individual schedules, N1 did share that sorting through all of the calendars does take a significant amount of time:

*"Per week I print 14 schedules of the different doctors and their PA's. And what I do is I go through them usually, there's me and there is one other nurse. And what I usually do is go through and each day or the day before I mark for the next day it may take a good*

*hour to really sit down and look through the system.”*

In addition to providers, communication between navigators proves important for the organization’s success. I already discussed how internal communication helps in sharing resources. Open communication and collaboration also assists navigators in managing the unpredictable nature of their work and their patients. N1 described a recent example:

*”Yesterday [the other nurse navigators] was out of the office at 4 o’clock, got a call one of her patients was in the hospital in a panic mode, needed somebody here now. So I just dropped everything. I went there and I stayed with him until she got there. So those are things we try to do, we’re good about helping each other with those kind of things.”*

Open communication also helps the cancer navigators provide emotional support to one another. The service navigators discussed how they would usually talk with one another after meeting with a patient, and hold an informal debrief.

Maintaining open communications between navigators also leads to positive effects on the patients, by providing an environment unlike other healthcare facilities. N2 and S2, respectively, shared their perception of this effect:

*”We’re almost like a family. And when they come here, it’s not a clinical environment, and if they’re having a problem with a doctor or they’re uncomfortable about something, this is a safe place and confidential.”*

*”There’s no task list. We know each other’s schedules and we know what’s going on in each other’s days. I think people that are used to being in an office, it sounds like we are just running amuck. But we’re not; we know what we’re all doing. And the patients really appreciate it because they’ll say ‘it feels like I just became part of your family’. They say, ‘I have my support system now’.”*

By using open and casual communication between navigators, the organization has also provided a system that promotes trust and communication with their patients.

### *Challenges*

The nature of cancer navigation provides navigators with the continuous challenge of re-

maintaining flexible while distributing their time to as many patients as possible. This challenge affects both nurse and service navigators, who all discussed the unpredictability of every patient meeting they hold. N2 specifically discussed the high degree of variability in regards to meeting times:

*"You don't ever know how a patient is going to handle something. You might speak with them 10-15 minutes or you could be caught up for 2 hours."*

Between organizing appointments around doctors' schedules and continuously holding meetings with irregular time intervals, communicating with stakeholders takes the majority of a navigator's day.

#### *Design Implications*

Future work should look at supporting cancer navigators' use of open and continuous communication with providers, patients, and other navigators as this communication greatly benefits the organization. Access to electronic medical records has already helped to alleviate some of the time constraints placed on nurse navigators. Hospitals and healthcare centers continue to implement technology that allows for greater interoperability, providing an increased level of communication between providers and other stakeholders. Cancer navigators should also be considered a primary stakeholder for future implementations. Elevating their role could be a critical step in allowing cancer navigators to spend more time with patients, and thus allowing them to reach a broader group of patients who could benefit from the navigation services. Tools that focus on awareness and allow a navigator to see when the other navigators are available may also help when unpredictable events occur. Ultimately, tools ought to promote flexibility and easier collaboration.

#### *Case Management*

##### *Current Strategies*

Over the course of a year, each navigator works with hundreds of patients, each with different needs. During cancer navigation, a paper file is created for each patient. This file

includes a needs assessment form, navigators' notes, and resource application forms, and is shared across the organization should a patient work with multiple navigators. These files are never thrown away; one navigator even discussed having a specific location for files of deceased patients. While managing caseloads of this magnitude can be complicated, each navigator developed their own personalized method for organizing patient files. S1 described how she places files in certain locations based on her perceptions of the patient:

*"I have my files that I put everybody in, but then, if I know they're going to be calling me I just kind of keep them, put them in a different spot, just so I can grab their chart when they call."*

While service navigators must manage a large number of files, they work entirely from the cancer navigation office building. Nurse navigators developed more complicated strategies to deal with the added mobility required in their job as they meet patients in surgery, chemotherapy, and radiation appointments. Any information or patient files a nurse navigator will need is organized by meeting date so that she can take a day's worth of files with her as she moves between healthcare centers. N1 described her personal strategy:

*"What I do is I just carry them for the day. The day's worth of files. I pick them up in the mornings because sometimes the doctors go in for an appointment and they may be so far behind and if you don't take your charts what's going to happen is you can't get back to the office to get them."*

Although each navigator's case management strategy was different based on where they stored files and when they moved files, each focused on the usage of paper files that included patients' needs assessments, personal notes on the patient, and copies of resource applications that had been submitted.

### *Challenges*

Large workloads place a great deal of pressure on memory and mental capacity. One of the service navigators mentioned struggling to remember patients' names when she runs into them unexpectedly. Further, N1 discussed the challenge of having such a high ratio of

cancer patients in the community to available navigators:

*"There's just so many cancers with two nurses there's no way we can cover them all."*

The office space required to store the files for all of the cancer navigation patients presents an additional challenge. Navigators store their files in several locations around the office including desks, drawers, and file cabinets.

#### *Design Implications*

Future research ought to examine ways to alleviate the cognitive load placed on cancer navigators working with a large number of patients. Over the course of a month navigators typically manage hundreds of patients.

Improved scheduling systems may help navigators remain adaptable for their patients. For example, scheduling tools that consider the amount of time a navigator spent with each patient in previous meetings could help navigators develop more accurate schedules.

Opportunities for technical implementations to help with file storage, thus saving office space may be particularly important for larger navigation organizations. Reminder based systems may also be useful in following up and tracking information for patients once they begin to meet with navigators less frequently. This shift usually happens once patients progress in their treatment and receive the resources for which they are eligible.

Technological implementations that educate communities about the navigation organization and their services may also help the limited number of navigators reach a higher percentage of cancer patients.

While a large variety of tools may be useful in case management, caution must be taken when introducing new technologies into cancer navigation organizations that support patients of low socioeconomic status. Technological implementations designed to support navigation work must take the physical environment under consideration. Many of the high-needs patients do not have access to technology. Since patients meet the service navigators at the cancer navigation center, obvious technological implementations may cause a disconnect between the navigation environment and the environments patients' are accus-

tomed to.

Preserving the casual atmosphere when navigators meet with patients may be important for maintaining relationships between navigators and their patients. The executive director of the organization described what a drastic effect a building's atmosphere can have on patients:

*"[We] had a gentleman who was a high needs patient. He was just really resistant to treatment and [S1] talked to him for a few minutes and realized his only pair of shoes was a pair of sneakers with the toes out of them, and so he was embarrassed to go to the fancy cancer center without decent shoes."*

This description illustrates one situation in which the environment itself directly impacted a patient's willingness to receive treatment. In order to prevent similar issues from occurring in the navigation center, technologies and changes made to cancer navigation facilities must consider impacts on the patients who work directly with the navigators and the environment navigators promote.

### *Long-Term Navigation*

#### *Current Strategies*

When mapping cancer navigators' responsibilities to the breast cancer journey, one can see that the work and services are heavily weighted towards the beginning of the journey. Many of the navigators mentioned that they try to follow up with patients when they get some free time to see how they are doing during or after treatment. However, large caseloads and high demands on their time limit navigators' ability to follow up with all of the patients, as mentioned by S2:

*"Once I actually give them everything they need, I'll keep [his or her file] next to me for a while then I get rid of it, I have to because our drawer is constantly filling up."*

#### *Challenges*

The large number of new patients that continue to need navigation support impedes on

navigators' ability to work with patients after treatment. According to one of the nurse navigators, as many as eight new consults may occur in a single day. This continuous influx of patients keeps the cancer navigators focused on patients in the beginning of their journey, so that they may help the new patients eliminate any barriers to beginning treatment.

### *Design Implications*

There is a growing need to provide ubiquitous care in chronic cancer management. Research shows that cancer survivors face physical and emotional challenges after completing treatment [31, 88]. For example, Rosedale found that "Survival loneliness," which includes feelings of loneliness caused by an increased awareness of mortality and changed sense of identity, affected survivors even 18 years after treatment [32]. In this study Rosedale also found that discussing their feelings of loneliness led survivors to feel relieved. This finding indicates that emotional support from navigators may help tackle survivorship challenges. Moving cancer navigation from a reactive to a more proactive system could greatly benefit their patients, especially the cancer survivors post-treatment. However, the current time constraints, as discussed above, greatly hamper on the ability for cancer navigation to move in this direction.

One way to assist cancer navigators in providing more long term support is to provide systems that allow navigators to be proactive and structure their follow ups with patients in more efficient ways. Technology in the area of home or continuous monitoring could provide this necessary aid. Projects such as Digital Family Portrait have demonstrated the utility of providing awareness to caregivers while retaining privacy and autonomy for the individual [89]. Similar projects could prove useful as a way for navigators to monitor the well-being of patients they no longer see regularly. This information could be particularly important in allowing navigators to use their time efficiently by being better able to assess from a distance the needs of these patients and gain a sense of which patients they should prioritize.



## *Development of Best Practices*

### *Current Strategies*

The development of best practices for cancer navigation falls outside the scope of the navigators' daily work. However, the advancement and expansion of cancer navigation requires the creation of these practices.

### *Challenges*

One of the biggest challenges in developing a set of best practices for cancer navigation programs is that many of the characteristics that promote the success of individual organizations inhibit the creation of standards. One such characteristic is that the backgrounds of the individual navigators help to define the expertise of their organization. The impact of individual backgrounds on the practice of navigation became apparent when discussing how the service navigators provide social security benefits for their patients. One of the service navigators originally worked for several years in the social security department, and brought to the navigation organization the knowledge of how to efficiently complete social security applications and help patients quickly receive their social security benefits. S1 expressed to us the significance of gaining that knowledge in the organization:

*"So now I know how to go online and look for the diagnosis that we know we are going to be covered. And then we print their policy and we highlight it to show them that we know they [the social security department] have 20 days to get this decision the patient goes, and within 30 minutes they are in and out of social security And it's all [S2]. If it wasn't for her, I had never heard of it and I've been in healthcare for 8 years and I had never heard of that. And so that's something that she's taught us."*

By leveraging individuals' backgrounds and expertise, this cancer navigation group is able to provide a broad range of services to their patients. However, since each navigation organization is comprised of people with various backgrounds, and no standard training program exists to capture this knowledge, there is currently no way for each organization to follow an encompassing and standardized set of best practices.

The high level of localization also makes developing best practices difficult. As previously mentioned, focusing on local impact has allowed the organization to develop processes that work best for the employees, patients, and local health clinics. The nurse navigators' strategy of accessing the doctors' schedules from the health clinics in order to attend all new consults is one example of a localized strategy. However, this process may not work in larger communities with more than three health clinics or in smaller, rural communities that do not have a nearby hospital. Thus, both the significant role of employees' backgrounds and the high localization of cancer navigation organizations hinder the development of national best practices for cancer navigation programs.

#### *Design Implications*

Scaling cancer navigation programs will require substantial work in the development of standard practices. I identified two key components absent from the current navigation structure that inhibit navigation growth: sharing of processes and standardized training.

As we discussed, the cancer navigators in this case study worked for years to establish processes and strategies that allow them to work efficiently and systematically. While organizations such as the one we investigated develop their own effective processes, such as the needs assessment process, no tools currently exist which allow separate organizations to share these practices with each other. Thus, each organization must develop their own practices despite the overlap of goals and tasks. Supporting the sharing of business processes can help encourage collaboration and enable the development of future cancer navigation organizations.

Another property not yet developed is a standard training model. Navigators did discuss learning new processes and resources by working at the organization. However, currently no standard training exists to use across multiple cancer navigation organizations. Thus the skills and materials that navigators learn remain highly localized, as do the organizations themselves.

Developing a social network for navigators may provide an initial technique for the cre-

ation standard practices. Through an online community navigators could share processes, experiences, and stories with one another. This tool may also promote a sense of community across multiple navigation organizations, fostering greater collaboration.

### *Summary of Design Opportunities*

Each of the themes described in this section help to identify areas for future cancer navigation support and expand the design opportunities for collaborative health technology. Table 4.1.4 provides a summary of the findings presented in each theme. All of these areas point to the need for technical support for the scaling of navigation practices. The reliance on informal communication means that current navigation organizations are limited to small teams that are vulnerable to serious disruption if a navigator unexpectedly leaves the group. These limitations also restrict the number the patients who may benefit from the personalized navigation services.

#### 4.1.5 Opportunities for future cancer navigation research

Through a detailed analysis of navigation practices in a rural community, I provide researchers with an introduction to navigation processes. Despite over twenty years of existence, only a small fraction of cancer patients are introduced to navigation services. In order for cancer navigation to experience the growth necessary to provide greater impact in cancer care, new tools and technologies will be needed. In the past, information systems that did not account for the high level of collaboration and flexibility in healthcare have failed [63]. As these are common HCI concepts, researchers in this field are uniquely positioned to develop the tools necessary to support complex navigation work. Further, the ability for future HCI research to assist in expanding cancer navigation, thus allowing more patients to benefit from their services, will be vital in developing an improved standard of patient-centric cancer care.

Current research investigating healthcare coordination primarily focuses on supporting

Table 4.2: Summary of Design Opportunities for Supporting Cancer Navigation

<b>Theme</b>	<b>Current Strategy</b>	<b>Challenge</b>	<b>Design Idea</b>
<b>Resource Monitoring</b>	Online Google searches Communication with other navigators	Resources are usually only available for patient beginning treatment	Tool that allows navigators across organizations to share search strategies
<b>Knowledge Transfer</b>	Print multiple doctors' schedules Open communication with other navigators to deal with unexpected events	Printing individual schedules is time consuming Navigators must remain flexible	Awareness tool that shows which navigators are available during an unexpected event
<b>Case Management</b>	Shared paper file created for each patient Try to call patients during down time	Work with over a hundred patients in a month	Scheduling tool that considers the amount of time a navigator spent with each patient in previous meetings to develop more accurate schedules
<b>Long-Term Navigation</b>	Navigation services focus heavily on the beginning of one's cancer journey	Continuous influx of patients keep navigators focused on new diagnoses	Continuous monitoring systems that allow navigators to check on former patients
<b>Development of Best Practices</b>	No current strategy, falls outside scope of navigators' daily work	Many characteristics that promote the success of individual organizations inhibit creation of standards	Social network systems that begin to foster greater collaboration and sense of community across organizations

doctors, nurses, and patients. As demonstrated with cancer navigators, when designing technologies for health systems, researchers must begin to consider healthcare professionals who work closely with patients and their information, but exist outside of the traditional patient-provider context. The analysis of cancer navigation begins to provide insight into new technological strategies for healthcare. I discuss two specific technologies that have the potential to support current navigation practices: collaborative information retrieval (CIR) systems and personal health records (PHRs).

Supporting collaboration across navigation organizations will be particularly important for enhancing navigation practices. Improving collaboration support will facilitate the development and maintenance of standard practices, afford the communication of a set of best practices between organizations, as well as potentially assist with regional and national resource management. One tool that successfully engaged collaboration in healthcare is the CIR system, which allowed users to share online search results with one another [90]. By developing this type of technology for navigation, cancer navigators from multiple organizations could share available patient resources with each other. This technology fits very well into current resource management practices as navigators primarily use online searches to find resources. By growing the pool of available resources for all navigators, the need to preserve resources may decrease. I also believe this technology could be vital in promoting communication across navigation organizations. Opening this communication will be a critical first step in sharing navigation processes and best practices on a national level.

In addition to CIR systems, PHRs have the potential to play a vital role in enhancing communication between navigators and patients, as well as between navigators and providers. Examining the themes knowledge transfer, case management, and long-term navigation reveals a need for better social connectivity. Regarding knowledge transfer, I discuss how nurse navigators need a more efficient way of monitoring schedules, so that they ensure that they are present for specific patient-doctor meetings. Within case man-

agement and long-term navigation I discussed the need for tools to reduce the cognitive load placed on navigators due to high workloads while also helping navigators remain in contact with patients after treatment. PHRs may provide a solution for all of these areas of interest. Many PHR technologies allow patients to designate a network of people who may access their health information. An easy to use PHR tool could allow navigators to see patients' medical appointments and health status both during and after treatment. Over time, PHRs may provide a new way for navigators to monitor and support patients when they are unable to meet face to face. Ultimately leveraging PHRs may further the broader goal of empowering patients in their own care by centering the care network on the patient and enabling the patient to activate that network when new needs arise. PHRs have already proved to be an interesting technology for researchers exploring healthcare cooperation [91]. Studying the impact of PHR usage by patients on healthcare facilitators, such as cancer navigators, remains an unexplored area. Investigating the use of CIR and PHR technologies provide potential areas for researchers to investigate in order to enhance navigation practices nationally.

#### 4.1.6 Summary

In this section, I provided a detailed description of a rural cancer navigation organization, specifically investigating the roles collaboration and technology play in supporting their work. Examining navigation from a sociotechnical perspective, we see that navigation is a collaborative care system requiring coordination with patients, providers, and other navigators. This study reveals a number of design opportunities for supporting navigation in the areas of resource monitoring, knowledge transfer, case management, long term navigation, and development of best practices.

Each of the design opportunities present challenges that could be considered in future work. Producing more case studies of cancer navigation organizations is necessary to increase our understanding of navigation trends at a national level and to reveal the impact of

localization on these organizations. Investigating a wider range of cancer navigation programs could also assist in developing a more cohesive national cancer navigation program. In the next section, I examine navigators' preferences towards health information sharing, and compare their preferences to those of their patients that partnering clinicians.

Many of the lessons learned from this case study can be applied to other cancer navigation programs or to programs with non-traditional health professionals who play similar roles. As researchers continue to try to understand and improve cooperation within the hospital and healthcare settings, we must consider ways of extending this cooperation to professionals who do not fall within the traditional hospital setting or role, but with whom coordination is imperative for supporting patients. As new technologies are introduced to health systems, an increasing amount of healthcare will occur outside of the hospital walls, making coordination increasingly complex and essential.

#### **4.2 Comparing health information sharing preferences of cancer patients, doctors, and navigators**

In addition to understanding cancer navigation practices, understanding the collaboration and communication practices between navigators, doctors, and patients is an important open question. Particularly when developing systems that involve tracking patient data, understanding the potential value that these stakeholders place on different aspects of the patient experience can help to determine opportunities for technology to support increased collaboration across the healthcare system.

Breast cancer care provides one area of healthcare that could greatly benefit from patients tracking and sharing health information. Cancer care is often modified for individual patients and one's symptoms and side effects can heavily influence the treatment plan [27]. Cancer treatment can often encompass a complex trajectory, distributed across multiple healthcare organizations. Thus, patients become responsible for communicating vital health data to help the medical teams monitor treatment impacts.

While patient self-monitoring and sharing of health information has the potential to benefit patient care, little work has identified whether the health information patients are willing to track and share aligns with the health information needs of the providers. By considering the relative needs of these distinct stakeholders, future tools could encourage patients to prioritize reporting health information that is of particular importance to their healthcare providers. Further, these patient centered tools may expand to provide greater collaboration between patients and providers.

In order to enhance our ability to develop tools that consider the needs of these multiple user groups, I compare the health information sharing preferences of breast cancer patients, doctors, and cancer navigators. I aim to call attention to the need for future health information sharing tools to promote greater collaboration between patients and their healthcare network, an area where HCI researchers can have a significant influence on improving patient experiences.

#### 4.2.1 Background

##### *Perceptions Toward Sharing*

Social computing research has identified many scenarios in which a person may wish to share different pieces of information, or provide different levels of access, to others [92, 93, 94]. In the health field, we see a desire from patients to share subsets of health information with selected groups. For instance, one study found that users of mobile health tools opted to share more information with strangers than with friends or family [95]. The Digital Family Portrait provides another example in which a subset of personal information was shared with family members [96]. These studies demonstrate the importance of understanding the social context that can influence sharing behaviors. In addition, a study examining diabetes patients found that these preferences and attitudes towards health information privacy can change over time [97].

Such studies help us gain an understanding of the personal beliefs and desires that



underpin health information privacy. I expand on this work by investigating the social and medical implications of health monitoring for the cancer care system, as the severity and complexity of the disease can bring additional challenges.

### *Benefits and Challenges of Health Tracking*

#### *Patient Perspective*

Personal health tracking can allow patients to receive the necessary help in stressful situations, directly influence treatment decisions, and improve health outcomes[98, 23, 99]. Health tracking practices can help mitigate limitations in the existing health system, in which a patient must recall as much information as possible during time- constrained meetings with their providers [100].

Continuous patient engagement brings new challenges alongside the benefits. Patients often must share basic medical information with concerned family members and friends. In parallel, patients may also track side effects to share with their oncologist to help in determining future steps and influence health outcomes [99]. Overall as the network of care enlarges, the burden falls on the patient to share the appropriate information with each person within their formal and informal healthcare networks [101].

#### *Provider Perspective*

For healthcare providers, including doctors and cancer navigators, the increase in patients tracking their own health provides a wealth of information. Such information can help doctors and cancer navigators to more efficiently focus their time [102]. While doctors and navigators will often work to assess patients' health status during appointments, a more accurate understanding of a patient's health situation can be gained by the patient providing his or her own assessments [103]. Receiving this health information prior to appointments can also allow a more direct focus on areas that require a doctor's or a navigator's attention during in- person patient meetings.

The challenge with utilizing this information is that these valuable data are not yet

regularly incorporated into healthcare treatment [100]. Providers have discussed viewing the information that patients track and add to PHRs as medically useful, especially when patients' medical records are not available [104]. However, these same providers did not have access to electronic records that could interoperate with the patients' own records. By providing more detailed insight into which specific health factors could benefit cancer providers, we hope to encourage the development of tools that support both patient health information sharing as well as the incorporation of the patient collected health information into cancer care.

#### 4.2.2 Methods

I designed this study to better understand health-sharing preferences of breast cancer patients, doctors, and navigators. I utilized surveys, interviews, focus groups, and a card sorting activity to elicit information from participants. All participants were a part of the Harbin cancer care system. To date, Harbin utilizes a process in which patients decide if they want to track and share their personal health information with their providers. The study provides foundational information to improve this process, alleviate some of the responsibility from the patients, and make available more relevant information to providers.

##### *Patient Surveys*

To understand patients' willingness to share health information with various groups in the cancer care network, I developed a survey that asked patients to identify whether or not they would feel comfortable sharing 23 different health information factors with 7 different groups of people. The health information factors include basic biometric information, physical side effects, and emotional issues pertinent in a cancer journey. Through discussions with cancer navigators, doctors and patients, I selected the health information factors that were relevant for breast cancer patients. To further ensure the appropriateness of the list, I asked participants of this study whether any important factors were missing. Partici-

pants commented that the list was comprehensive.

The final list of health factors included two biometric factors, fourteen physical health factors and nine emotional factors. Biometric factors included height and weight. Physical health factors included pain, nausea, constipation/diarrhea, fatigue, hot flashes, sleeplessness, hair loss images, medication adherence, surgery details, cancer stage, survival statistics, scar images, breast images, and diet. Emotional factors included stress, anxiety, loneliness, fear, seeking support, 'I am having a good day' and 'I am having a bad day'. Height was used as an initial factor that possessed few emotional implications as a way for patients to get acclimated with the survey questions.

In the survey, patients were asked to indicate for each factor whether or not they would feel comfortable sharing the information with the following groups: Me, Caregiver, Navigator, Oncologist, Social Media, and Society.

'Me', as explained to participants, was a way for a person to indicate whether each health factor would be something they were interested in monitoring themselves throughout their cancer journey. 'Caregiver' was used to represent any person in the patient's health network who helps look after the patient (usually a close relative or friend).

'Navigator' was used for asking whether or not patients would share health factors with their cancer navigator.

'Social Media' represented any social networking sites used by participants. Many of the participants engaged to a various degree with Facebook and other social media. For participants who did not, I asked them whether or not they thought they would feel comfortable sharing the information online. 'Society' was used as a means to ask patients if they would feel comfortable sharing certain health information in public settings, such as a public forum or open cancer awareness event.

I asked about these distinct groups in order to gain a more holistic view of patients' health information sharing preferences as they relate to their entire healthcare network. For the purpose of this study I focus on their preferences for sharing health information with

Table 4.3: Health information sharing preferences: Sample of data collected

<b>Willing to Share?</b>	<b>Me</b>	<b>Caregiver</b>	<b>Oncologist</b>	<b>Navigators</b>	<b>Social Media</b>	<b>Society</b>
<b>Yes</b>	Height, Weight, Pain, Nausea	Height, Weight, Pain, Nausea	Height, Weight, Pain, Nausea	Height, Weight, Pain, Nausea	Height	Height
<b>No</b>					Weight, Pain, Nausea	Weight, Pain, Nausea

their doctors and navigators.

#### *Patient Interviews*

To compliment the survey, I wished to gain a deeper understanding of the thought process used to decide what information patients were willing to share with the various groups. I developed a card sorting activity that mirrored the information collected in the survey. In the activity, the health information factors and groups were written on cards. The groups were placed along the top of a table to create individual columns. Patients would then receive the health factor cards. For each group, the patient would place the health factor card in one of two piles below the group heading to indicate whether they would or would not be willing to share that health factor with that group. During the activity patients were encouraged to think aloud and the interviewers would occasionally ask probing questions to better understand the thought process. Table 4.2.2 shows a sample of data collected after a patient went through the first four health factors.

All interviews took place in the cancer navigation office and lasted 1-2 hours. I found that responses from the interviews were comparable to the survey responses, while providing some additional information about the thought process behind the results.

### *Patient Participants*

The survey was sent out to 67 breast cancer patients in the Rome, GA community. I also ran interviews with four additional patients (represented in this paper as P1-P4). All patients were female and had been diagnosed with breast cancer within the past year. Patients' average age was 60 years old. Patients had varying stages of breast cancer and treatment plans, but all received treatment in Rome, GA.

I received 20 survey responses (a response rate of 29.9%). Three of the survey responses were removed from the analysis because the participants marked the same answer for each question. When combined with the responses from the four patients who participated in the interviews, we analyzed a total of 21 patient responses.

### *Doctor Focus Group*

In addition to understanding how patients felt about sharing health information, I wished to get a sense of the types of patient information doctors would be interested in monitoring. I ran a focus group with three doctors: a medical oncologist, a radiation oncologist, and a general surgeon. All three doctors work with the breast cancer patient population described above. I conducted a focus group as opposed to individual interviews due to the preferences and availability of the doctors.

With these doctors I ran an activity similar to the card activity used with patients. For every health factor, each doctor stated their interest in receiving and monitoring information about that factor collected by their patients, and whether or not they currently collect that information. Upon completion, I asked the doctors to rank the health factors they were most interested in monitoring. This ranking allowed us to gain an understanding as to which features would be necessary on future health monitoring tools to encourage provider use.

### *Cancer Navigator Interviews*

I ran the same card activity with two of the cancer navigators (represented in this paper as N1 and N2). Both navigators were nurse navigators. Nurse navigators' work straddles the medical and emotional aspects of the cancer journey and they deal directly with many of the health factors included in the patient survey. Interviews were conducted with each of the navigators individually due to their differing availability.

### *Data Analysis*

Two researchers reviewed the survey and interview data. I used an iterative analysis to cluster segments from the survey responses and transcripts and develop thematic concepts. Researchers focused on preference reasoning, discrepancies between sharing preferences, and technology design implications. We reviewed each other's analysis and came to a consensus on the themes.

#### 4.2.3 Findings

In this section I provide an overview of the doctor, navigator, and patient responses, summarized in table 4.2.3. I then examine some interesting factors that influenced patient preferences, including patient assumptions, cancer identity, and concerns about imposing on others. Finally, I examine the misalignment between patient and doctor responses.

### *Doctor Responses*

The focus group activity with the medical oncologist, radiation oncologist and general surgeon revealed that eleven of the health factors would be important to all three doctors for continuous monitoring. These factors included both biometric factors (height and weight), four physical factors (nausea, constipation/diarrhea, hot flashes, and medication adherence), and five emotional factors (stress, anxiety, loneliness, fear, and seeking support). The medical and radiation oncologists were interested in an additional four physical

factors: pain, fatigue, sleeplessness, and diet. While this list includes many distinct factors to track, all three of the doctors emphasized that the combination of information across many factors would be important in allowing them to better understand the context when issues do occur.

When asked to rank the factors in terms of their importance, each doctor agreed that pain, nausea, and constipation/ diarrhea are typically the most important as they can greatly influence a patient's daily life. However, the doctors also stated that these can change depending on the patient, and anything that could negatively impact quality of life will be important for the doctor to monitor. As the general surgeon noted:

*“The quality of life issues [are most important]. Most patients, if you ask them, their goal is to have some semblance of a good quality of life. Well, you can't have a good quality of life if you're in pain all the time, if you're sick, if you're having diarrhea These are things that really impact their day to day.” - surgeon*

Thus, based on the doctors' feedback, health tools that monitor a range of quality of life factors, including both physical and emotional factors, will be most beneficial to them, despite the large amount of information.

### *Navigator Responses*

Both navigators stated that they currently talk to patients about eleven of the health factors. These include six physical factors (pain, constipation/diarrhea, fatigue, medication adherence, surgery details, and cancer stage) and five emotional factors (anxiety, stress, loneliness, fear, and 'I am having a bad day'). In the future, the navigators discussed a desire for health tracking tools to include these factors. Both navigators were also interested in including nausea and sleeplessness to their practice through future tools. N1 expressed interest in monitoring additional health factors, including height and weight (due to their impact on BMI), diet, seeking of support, hair loss images and scar images. N2 stated an interest in monitoring hot flashes.

The main similarity between the two rankings is that loneliness is viewed as critical to both of the navigators, ranked first and second in their individual orderings. However, when looking at their top ten ranked health factors we can see differences emerge. N1's top ranked health factors included (in order) loneliness, surgery details, pain, medication adherence, constipation/diarrhea, nausea, fatigue, stress, sleeplessness, and weight. N2's top ranked health factors included cancer stage, loneliness, anxiety, fear, stress, surgery details, fatigue, diet, pain, and constipation/diarrhea.

Looking at these rankings side by side, N1 focused more on medical issues while N2 ranked the emotional issues higher. These differences were primarily due to the fact that the navigators work with different groups of patients. N1 works with a wider range of cancers than N2, who works exclusively with breast cancer patients. A broader array of health challenges result from the additional cancer diagnoses. Ultimately, such variations demonstrate the need for health tracking tools designed for cancer navigators to include both physical and emotional health factors. Further, tools must be agile so that they may be tuned to best serve the individual journey of the patient.

### *Patient Responses and Motivations*

Table 4.2.3 shows the percentage of respondents who indicated a willingness to share each health information factor with their oncologist and navigator. The table shows that overall patients are willing to share their health information with doctors and cancer navigators. The interviews provided some additional context around these responses, particularly into how patients make health information sharing decisions. Here I discuss three influential factors that arose during conversations with patients.

### *Assumptions*

Two assumptions made by the patients seemed to drive information sharing preferences. The first assumption dealt with the perceived interest of the receiver, while the second assumption focused on the receiver's ability to help the patient. When looking at these



Table 4.4: The percentage of patients who indicated a willingness to share the health factor with their doctor and navigator, and the health information sharing preferences of each of the providers

<b>Health Factor</b>	<b>% patients willing to share with doctors</b>	<b>% patients willing to share with navigators</b>	<b>General Surgeon</b>	<b>Medical Oncologist</b>	<b>Radiation Oncologist</b>	<b>N1</b>	<b>N2</b>
<b>Height</b>	100	100	X	X	X	X	
<b>Weight</b>	95	81	X	X	X	X	
<b>Pain</b>	100	95		X	X	X	X
<b>Nausea</b>	100	90	X	X	X	X	X
<b>Constipation</b>	100	90	X	X	X	X	X
<b>Fatigue</b>	100	95		X	X	X	X
<b>Sleeplessness</b>	100	95		X	X	X	X
<b>Heat Flashes</b>	95	90	X	X	X		X
<b>Hair Loss Images</b>	90	76				X	
<b>Medication Adherence</b>	100	90	X	X	X	X	X
<b>Surgery Details</b>	100	95				X	X
<b>Cancer Stage</b>	100	100				X	X
<b>Survival Statistics</b>	100	100					
<b>Scar Images</b>	90	86				X	
<b>Breast Images</b>	90	71					
<b>Diet</b>	86	90		X	X	X	
<b>Stress</b>	71	86	X	X	X	X	X
<b>Anxiety</b>	86	90	X	X	X	X	X
<b>Fear</b>	71	76	X	X	X	X	X
<b>Loneliness</b>	76	71	X	X	X	X	X
<b>Seeking Support</b>	86	86	X	X	X	X	
<b>Good Day</b>	90	86					
<b>Bad Day</b>	86	81				X	X

assumptions alongside conversations with the doctors and navigators we begin to see that these patient assumptions do not always align with the beliefs of doctors and navigators.

### 1. Perceived Interest

The first assumption that influenced information sharing was whether or not the patient thought the receiver cared about the information. For example, P2 specifically stated that she would not share feelings of nausea on social media because her friends on social media “don’t really care.” Perceptions of interest also motivated the sharing of information. P2 stated that she was willing to share her fear with her family and cancer navigators:

*“Caregivers, they really want to know that because they’re afraid, they’re very afraid for you. Navigators, they want to be there [for you].” - P2*

### 2. Ability to Help the Patient

The second assumption patients mentioned involved the ability for the receiver to help the patient with her issue. In general, this was discussed in interviews as a reason for not sharing health information. For example, P3 discussed a previous experience in which she chose not to tell the doctors about the side effects of her treatment:

*“I never usually have swelling but the first time I took Tamoxifen, I took it on a Friday night. The next morning I woke up and my hands were like the Pillsbury Doughboy’s. My fingers were swelled together. I’ve never seen anything like it. And doctors said ‘you should have come to the emergency room.’ And I said ‘Well, and what would you have done? Nothing.’ So I just kind of watched it.” P3*

In this situation, an assumption led a patient to not share health details with her doctor. Such an example demonstrates the need to make the ways in which doctors can help with managing certain symptoms and side effects clear to patients. These perceptions help explain why patients and doctors did not always concur on what information ought to be shared with one another. In the next section, I explore this finding in greater detail, describing how this misalignment can hinder a patient’s cancer care and how future technologies may help ameliorate this gap in care.

### *Cancer Identity*

A surprising result that emerged from discussions with cancer patients was the association between a patient's assumed cancer identity and the willingness to share health information.

N1 described to us how she has witnessed patients adopt varying cancer identities:

*"Sometimes cancer is a small part of their lives, and they'll say 'cancer is a small part of my life and I'm not going to let it dictate my future, it's not my whole life.' And then sometimes cancer becomes they get stuck in that. That's their whole life." N1*

My conversations with patients helped to reveal the way in which they perceive their cancers differently. For example, P2 described her cancer as a small hurdle:

*"I feel like this is a bump in the road, you get over it, and you move on down." P2*

When examining P2's sharing preferences, she spoke of being open and willing to share symptoms such as nausea, fatigue, and pain with her doctors, caregivers, and navigators. She was also comfortable sharing some information on social media, such as feelings of stress, anxiety and her diet. For society at large, P2 said she would be willing to share her experiences with hair loss, stress, anxiety, diet, and seeking support. The dialogue centered on sharing in an effort to overcome the disease and to help others. In contrast, P3 seemed to disassociate herself from the cancer:

*"I just didn't want any one to know. Except my own children know, and my brother and sister in law know I try to act like I don't have it I guess. I don't want to be my cancer." P3*

This perspective also seemed to affect her willingness to share health information. In general, P3 was less comfortable sharing health information. She was less willing to share information with the cancer navigators and said she would not discuss some personal health details, such as weight or constipation/diarrhea side effects with her caregiver. Further, she would not share any health information on social media or society at large. P3 also said that throughout treatment other people in her life, such as her boss, did not know about her diagnosis because she didn't want to be seen as a cancer patient. When discussing her sharing preferences for health information generally, P3 focused mainly on protecting her

privacy.

These contrasting viewpoints help to provide a glimpse into the types of personal traits that can influence a patient's willingness to share health information. Future research could delve deeper into the influence of a patient's cancer identity on daily behavior and relationships with others.

#### *Imposing on Others*

The desire to not impose one's problems on other people seemed to cause some patients to share less personal health information. P1 specifically stated that she tries to keep her pain to herself because she doesn't want to bother other people. P4 also stated that her desire to not "whine and complain" caused her not to share information on social media or to society at large. Further, P4 stated:

*"I tend to even with [my husband and children], not want to complain, put a pretty good face on it And you know, not wanting to trouble them or worry them, so a lot of times I just won't share things that I think will hurt them or upset them." P4*

Other studies have noted similar results in which patients wished to "maintain positive impressions" around the people close to them [105]. Interestingly, a patient taking on this burden to deal with issues and side effects by herself was apparent to the cancer navigators. N1 described a conversation she has with numerous patients. When she asks patients "why have you been hurting for two weeks and you didn't tell me?" A common response from the patient is "I didn't want to bother you."

#### *Patient/Provider Discrepancies*

Through the results described above, and summarized in table 4.2.3, we can see that some misalignments between patient, doctor, and navigator preferences exist. For instance, some health factors were only of interest to the cancer navigators, and yet fewer patients were willing to share this information with their navigators than with their doctors. This misalignment can be seen in the responses to health factors such as hair loss images and 'I

am having a bad day’. Also apparent in table 4.2.3 is the willingness and interest patients possessed to share health factors that were not of interest to any of the providers. This can specifically be seen in the breast images factor, in which 90% of patients said they would be interested and willing to share these with their doctors. These misalignments begin to show the need for technologies that help focus patients’ health tracking and sharing behaviors, so that they may better support the needs of their healthcare network.

The health information sharing preferences surrounding the emotional factors lead to some interesting discrepancies as well. As I discuss below, I have found inconsistencies dealing with loneliness and patient satisfaction.

#### *Loneliness Gap*

The findings revealed that 24% and 29% of patient participants stated they would not share feelings of loneliness with their oncologist or navigator, respectively. P2 stated she would not share loneliness because “doctors really don’t care if you’re lonely.” Other patients discussed not sharing emotional factors, such as loneliness, because they did not feel that doctors could help in coping with these emotions. However, the medical oncologist gave an example of a recent patient to describe why communicating feelings of loneliness can be so important:

*“If any one of these [factors] is off the charts it could be bad. It could be loneliness. I had a woman today. I was like ‘how are we going get her home?’ She won’t reach out to her best friend. And because of that she’s scared to death, and because of that she’s scared about coming in to treatment and doesn’t know if she wants to do it. And it all stems from loneliness.” medical oncologist*

The navigators also brought up loneliness as an issue. Both navigators ranked loneliness high on their list of important health factors to monitor, but recognized that patients do not always share this information outright. Sometimes it falls on the navigator to identify hints that loneliness may be an issue for a patient. As N1 described:

*“Loneliness is something that is very shameful and embarrassing to them. So if I sense*

*that this person is alone I need to be there a lot more then.” N1*

This “loneliness gap” begins to show that some misalignment exists between what patients, doctors, and navigators each feel are important health factors to share. The navigators noted that emotional issues are generally the most challenging for patients to share, specifically referencing loneliness, fear, and anxiety.

Addressing this gap carries two main challenges. First, in order to track loneliness or other emotional issues, a useful measurement must be utilized. As the general surgeon noted: “I don’t know how you would define loneliness.” The second challenge involves increasing patients’ willingness to share loneliness issues with their doctors and navigators. This may be possible if health-tracking tools highlight doctors’ interest in emotional issues and how they may be able to help the patient.

#### *Tracking Patient Satisfaction*

Although I did not specifically ask about patient satisfaction, stories concerning their satisfaction with the health system came up frequently in conversations with patients. For instance, P2 shared one memorable moment with us:

*“I remember one time I was going through a depression. I remember going to [my doctor], and he was busy writing, he had his back turned to me and I was on the exam table. And I said things are pretty rough, I feel pretty sad. And he never even looked at me.” P2*

Following this situation, P2 told her doctor directly that their interaction had upset her and received positive results in return. She stated that following that incident and subsequent discussion her doctor makes a more concerted effort to shake her hand and focus on her during appointments. However, not all patients are as willing to confront their doctors. For example, P3 shared that she once felt extremely upset with her care when she felt that she could not reschedule one of her radiation treatments:

*“I don’t like being treated like that. I like having a choice. And it was never made clear to me why I didn’t have a choice. [My doctor] would want me to tell him, but I just, I just*

*can't. Because, number one, they're not going to change." P3*

Clearly, experiences like these can leave lasting impressions on patients. P3 finished treatment several months prior to the interview, but got visibly upset when sharing this story, showing the long-term emotional impact of patient satisfaction during the cancer journey.

Interestingly, patient satisfaction also leaves lasting impressions on the doctors. In the focus group, the doctors also brought up patient satisfaction and their desire to have patients share their feelings and negative experiences with them earlier. The general surgeon discussed his desire to improve the cancer care experience for his patients:

*"You find out sometimes after you've gone through the entire process that somebody early in the course of care was unhappy about something. It would be nice if somewhere they were keeping a log that we had access to that says how happy are they with the way things are going. It gives us a chance early on in the care to realize [we have a problem]. But we can solve it. What happens is the problem has already occurred and three months later comes to my office. Well, I could have fixed that. Give me real-time data. Let me affect the patient's experience by knowing their not having a good experience. I can do something about that. Give me an opportunity." - surgeon*

Similar to the issue of loneliness, some patients revealed feeling hesitant to share dissatisfactions about their healthcare to their doctors. Notifying doctors of satisfaction issues through technology may help alleviate the challenge of confronting the doctors directly. Ultimately, a more defined process for tracking and sharing emotional issues and enhanced communication between doctors and patients may help to address these contrasting preferences.

### *Summary of Results*

Table 4.2.3 provides an overview of the health information sharing preferences across patients, doctors, and navigators. Surprisingly, all of the providers indicated a need to receive

a set of both physical and emotional health factors. Further, they all preferred receiving a wide range of health factors, which provide greater context but take more time to monitor and understand. I also found several factors that can influence patients' willingness to share, including assumptions about others' interest and ability to help, patients' cancer identity, and concerns about imposing on others. Through a comparative analysis, I identified discrepancies between patient, doctor, and navigator health information sharing preferences. Such misalignments point to the need for future tools to help bridge the needs of healthcare providers with the behaviors of patients engaging in personal health tracking.

#### 4.2.4 Implications for design

Cancer care is becoming an increasingly collaborative process between patients and providers. While existing tools such as PHRs and symptom trackers help patients collect health information, research has yet to examine whether this information aligns with the health information needs of healthcare providers, such as doctors and cancer navigators. I examined the health information sharing preferences of cancer patients, doctors, and navigators in order to explore how future tools can incorporate the needs of these stakeholders and enhance the utility of patient collected information in their healthcare.

In reflection, these findings highlight four specific design implications. These implications aim to reduce discrepancies between patients, doctors, and navigators' sharing preferences. For these design opportunities I also discuss challenges that ought to be considered in the development of future health information sharing tools.

##### *Allow Recipients to Select Important Health Factors*

Undoubtedly, patients need control of their health tracking tools. Providing control not only to the patient but also allowing those in a patient's healthcare network to select which factors they want to receive may help increase the utility of health trackers. The main motivation for this feature is that I saw discrepancies between each of the doctors and nav-



igators regarding which features they were interested in monitoring. Today, health information tracking and sharing tools place the responsibility on patients to decide with whom to share [106]. Providing this feature to a patient's healthcare network may also help to reduce the concern patients felt about sharing health information with people who did not care about that particular information. Allowing recipients to select the information they wish to monitor may help alleviate the burden placed on patients of trying to guess who in their healthcare network should receive select health information.

#### *Challenge: Determining Frequency of Sharing*

Allowing both the sharer and recipients of health information to influence the sharing process does bring additional questions that ought to be considered in future designs. Determining how often patients should share health information with their doctors and navigators remains an open question for health tracking processes. Capturing and sharing health information more frequently requires a greater time commitment from patients. However, less frequent sharing hinders the potential benefit of health tracking tools to provide early warning signs that health problems are hurting a patient's quality of life.

When asked about current sharing processes, each of the doctors and navigators stated that patients brought up health factors "when there is an issue." While all of the participants agreed that more frequent sharing would benefit the cancer care process, the appropriate pace of health information sharing was not identified. Examining how different sharing frequencies influence health-tracking practices could greatly help the design of future health tracking tools.

#### *Support Sharing of Past Experiences*

An important feature for future health information sharing tools and processes is the ability for patients to learn from the past experiences of providers and other patients. This need falls under broader requirement to educate patients about how providers can use the information they share. I found that some patients hesitate to share information if they don't

think the person receiving the information can help. Demonstrating how sharing health information with others can benefit the patient will be important for showing the full value of such tools to patients. Previous work has examined how peer support can be enhanced in cancer care [107, 23]. There remains an open opportunity for tools to allow new patients to learn from the experiences of doctors, navigators, and other patients. Particularly, revealing experiences in which health information sharing behaviors benefited the patient can help provide context around the importance of these practices. Such tools may help to eliminate the discrepancies between health information sharing preferences identified in this research.

*Challenge: Permanency of Shared Information*

In the development of tools that allow patients to learn from others' previous experiences, designers must consider the permanency of the information being shared. The benefit of retaining health information is that such information could be used to help future cancer patients. Several of the participants described a willingness to share information in an effort to help others. Thus, if the health information that patients share with doctors, navigators, and the broader society can be maintained past their cancer treatment, it may provide valuable insight for newly diagnosed patients who are experiencing similar situations. However, sharing personal health information can also have negative lasting consequences

P3 discussed with us the negative impact sharing health information had on her life. Prior to her own diagnosis, P3's husband had been diagnosed with terminal cancer. P3 shared with us that because everyone in the community knew about her husband's diagnosis and the negative symptoms of his disease, she felt as though his cancer unwillingly became a part of her identity. P3's feeling that people identified her as "the cancer patient's wife," prevented her from sharing with others her own cancer diagnosis, even years after her husband's diagnosis. This story provides one example of how health information permanence negatively influenced one patient's cancer journey. Similar to selecting the types of information shared, patients may need control over the permanency of the information

being tracked, and possess the freedom to change the information that is shared over time.

### *Minimize the Burden of Sharing*

One surprising result that emerged from this study was the broad range of health factors all of the doctors and navigators wished to receive from patients. Each of these stakeholders requested at least eleven distinct factors. This desire for extensive health information sharing conflicts with the general desire to reduce the time that patients must spend focused on health tasks. As previously stated, all stakeholders, including patients, doctors, and navigators ought to influence the information that is shared between one another. Once these preferences are set, however, scaffolding sharing processes to minimize the burden may help provide doctors and navigators with rich context while reducing the need for patients to continually think about which information ought to be shared with whom.

### *Challenge: Respecting Patient Privacy*

Previous studies have shown that patients prefer to share different health information with the various people in their lives [97]. Tools may need to provide this level of control to patients in order to encourage continuous use. However, this control over information sharing can also threaten patient care if patients opt not to share important health information with their doctors. Thus, a significant issue with health tracking is respecting patients' sharing decisions even when such decisions may impede on their cancer care. Including explanations within health tracking tools of how and why providers may use shared information to improve the cancer care process for a patient may help alleviate this challenge. Future work should look at how the health information sharing preferences of patients, doctors and navigators can be made more transparent to each other, as this may help to align sharing preferences.

### *Utilize Healthcare Network Collaboration in Design*

My discussions with doctors, navigators, and patients made apparent the need to include all of these stakeholders in the design process of future health information sharing tools. In the conversations, participants suggested interesting design ideas based on their own experiences. For example, N1 shared a typical discussion about pain:

*“I always ask them on a scale of 1 to 10, and can you describe the pain to me. That helps me a lot. Is it throbbing, is it a dull ache, is it over here, is it shooting through the abdomen. The location of it helps a lot. And they are usually pretty descriptive.” N1*

Integrating design features that mimic these types of conversations could help health tracking tools provide greater context about a patient’s health situation. Further, such features may be easier for doctors and navigators to monitor as they correlate with their existing methods for understanding patient symptoms and side effects. Doctors also brought a unique background, posing a new set of possible future designs. They presented ideas such as combining health-tracking tools with the existing psychosocial distress screening (a 2015 healthcare requirement). The diverse design ideas posed by navigators, patients, and doctors highlight the significant help each can provide to the design of health tracking tools. I strongly encourage researchers to consider their input throughout the design process. Involving these and other stakeholders may also encourage a sense of ownership over tools, helping to remove the ever-present challenge of engaging users over an extended period of time.

### *Challenge: Developing Standard Measures*

In discussions with these stakeholders, the challenge of measuring many of the health factors in a meaningful way came up frequently. Survey respondents also commented that measuring some of these factors would be difficult. For example, as the radiation oncologist noted, “how do you collect pain?” A Likert scale selection of 7 most likely does not provide enough context around how the patient is feeling. I found that participants held different opinions on how best to measure specific health factors. A challenge for future

technologies will be to utilize standard measurements for complex factors such as pain or loneliness that are meaningful for all of the users involved in the design and the use of such tools.

#### 4.2.5 Summary

The goal of this study was to support the development of useful health information sharing tools that allow providers to more easily utilize information shared by patients. Results indicated a general interest by doctors, navigators and patients to utilize health-tracking tools that include a range of health factors. Both doctors and navigators preferred robust tools despite the potential increase in complexity. The importance of context in understanding cancer patient health issues motivated this need for a broader range of health information.

While patients revealed an overall comfort level in sharing personal information with their doctors and navigators, I identified some discrepancies between health information sharing beliefs. Specifically, emotional issues such as loneliness and satisfaction with care provide challenges, as patients are not always comfortable sharing these issues. Future health-tracking tools may be able to better align the sharing preferences of doctors, navigators, and patients, allowing for health information tracked by patients to be better integrated into the care they receive. To support their development, I identified design implications and challenges to be considered in the design process. A key challenge with managing longer health journeys is the lack of available ubiquitous care. This study contributes to our understanding of how technologies may help provide more continuous care during people's everyday lives.

### **4.3 Discussion**

The two studies described in this chapter each examine aspects of existing cancer care practices, helping to answer the research question: *What are the strengths and limitations of existing healthcare practices that help patients manage their health over time?*

Collectively these studies highlight important guidelines for patient health tools. In particular, navigators and oncologists emphasized the diversity of patient experiences and the importance of flexibility in supporting unexpected issues. They also revealed the breadth of factors that can become barriers to health management. Such factors span beyond physical health. For example, cancer navigators and oncologists stressed the importance of social and logistical support, and the severe impact a lack of support in these areas can have on patients ability and willingness to receive care. Existing care practices also face several challenges in supporting patients throughout the cancer journey. Navigators and oncologists faced significant time constraints, making them less available to offer continuous support as patients progressed through treatment. Further, patients did not always feel comfortable sharing their personal issues with their health providers. Technology may therefore support existing practices by offering continuous support to patients when health providers are unavailable, and for providing a mechanism for patients to receive support for issues they do not wish to share with others. In chapters 6 and 7, I describe how I used these guidelines in the design of a novel patient health tools, with the explicit goal of developing mhealth interventions that offer the comprehensive and flexible support. These studies were also invaluable in developing a partnership with cancer navigators, who played a critical role in the MyJourney Compass and MyPath deployments.

## **CHAPTER 5**

### **THE PATIENT’S PERSPECTIVE OF THE CANCER JOURNEY**

In this chapter, I describe a study that helps to answer the research question: *What are the key dimensions in a comprehensive, holistic view of cancer journeys from the patient perspective?* My work with cancer navigators, described in the previous chapter, revealed that cancer journeys, encompassing patients’ cancer experiences from diagnosis through survivorship, are complex and diverse. Individuals dealing with cancer must cope with numerous physical and emotional challenges, balancing clinical tasks alongside the responsibilities of daily life. Understanding the breadth of factors that contribute to a patient’s cancer experience presents a critical challenge in developing holistic patient-centered technology. To further our understanding of the cancer journey, I conducted focus groups and interviews with 31 breast cancer patients. I present a cancer journey framework depicting the responsibilities, challenges, and personal impacts patients face while transitioning from diagnosis through post-treatment survivorship. The framework highlights how each of these responsibilities, challenges, and personal factors change over the course of the cancer trajectory. Through this work, I aim to support the development of health tools that consider a patient’s cancer journey and health needs more broadly, supporting patient’s health management alongside the complexities and priorities of daily life.

#### **5.1 Methods**

##### 5.1.1 Data collection

I ran interviews and focus groups with breast cancer survivors. Through the initial interviews, participants reflected on their cancer experiences, support needs, and the ways in which they used technology throughout the cancer journey.

In a follow up study, I ran focus groups to elicit discussions about the cancer journey in particular. Each focus group consisted of two to four participants. I asked participants to write down significant moments related to seven categories: medical; family and friends; work and finance; moments of change; problems or challenges; emotional highs and lows; and anything else that characterized their journey. I arrived at these categories based on the conversations with cancer navigators. I specifically asked participants to write or draw, as prior research has shown that this modality assists people in expressing their overarching mental models that are conceptually complex [72]. By the end of the activity, each participant had developed a personal reconstruction of the cancer journey (figure 5.1). I recorded and transcribed all discussions.

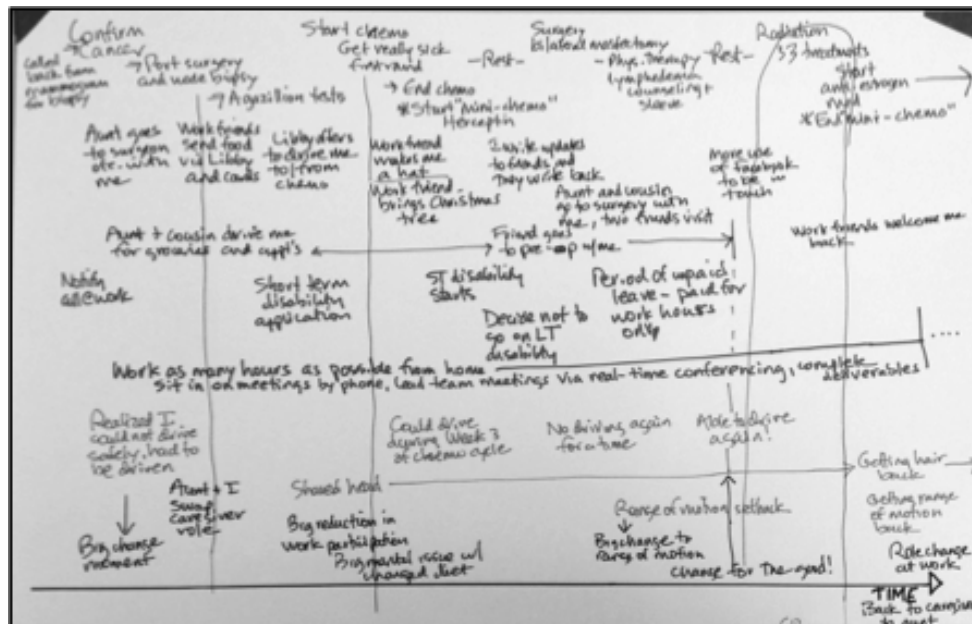


Figure 5.1: Sample cancer journey reconstruction

In total, I interviewed 17 participants and conducted four focus groups with 14 participants. All 31 participants were going through or had recently completed treatment, including surgery, radiation, and/or chemotherapy. The majority of interview participants were receiving cancer treatment at the time of the interviews. Focus group participants had completed active treatment and were beginning hormone therapy, with the exception



of one participant who had not yet begun her chemotherapy treatment at the time of the focus group. All participants were recruited through and received treatment at the same cancer clinic in northwest Georgia. Participants' ages ranged from 39-80, and all had been diagnosed with breast cancer stage 0-III.

### 5.1.2 Data analysis

The final dataset consisted of 14 cancer visual narratives and 29 hours of transcription. In total, the dataset included 1,126 quotes that described personally significant moments that affected patients' cancer experiences. Once I aggregated the data, five researchers individually reviewed the data and independently engaged in an open coding exercise. All researchers then compared codes and collaboratively developed an initial codebook. Through a subsequent iterative inductive analysis, we developed a finalized set of codes, organized into the high-level themes included in the cancer journey framework.

I organized findings across four overarching cancer phases used in related literature [27]: screening and diagnosis, information seeking, acute care and treatment, and no evidence of disease. While not all patients follow this treatment path, the phases help to demonstrate how patients' needs and priorities shift over time, a critical component to consider when designing health tools.

## **5.2 Findings**

I organized results into three categories: responsibilities, challenges, and how the cancer journey influenced patients' daily life (their personal journey). The 'responsibilities' category highlights the multiple tasks that are placed on patients during each of the cancer journey phases. 'Challenges' includes specific issues participants encountered that served as barriers to receiving quality healthcare. Alongside these health-specific factors, all participants also grappled with dealing with cancer in the context of their daily lives. This part of the cancer journey can be unique to the individual, as each participant defined cancer

in her own way. The ‘personal journey’ is patient-driven, changing based on participants’ individual goals and needs.

Table 5.2 shows the cancer journey framework, depicting how patients’ responsibilities, challenges, and personal journey change over time. While I present each finding within the phase of the journey where participants most frequently described these themes, patients’ cancer experiences are personal and unique. Thus, the responsibilities, challenges, and personal factors may be present in several phases of the journey depending on an individual’s personal experiences.

### 5.2.1 Screening and diagnosis

This phase of the cancer journey typically begins when a patient experiences symptoms or participates in scheduled preventive screenings. Participants shared a number of responsibilities and challenges, showing the immediate effects a cancer diagnosis can have on one’s life.

#### *Responsibilities*

Upon diagnosis, 16 participants revealed they felt immediately responsible for communicating the disease to others. Telling children about the diagnosis was particularly difficult for participants. Four participants recalled trying to stay positive during this particular discussion. Another four participants stated that telling children and grandchildren, while difficult, was a very important educational moment, as ensuring their family understood the diagnosis and family risks became a priority.

#### *Challenges*

One significant challenge 14 participants highlighted involved dealing with information gaps, or information they wish they had possessed. The most common gaps included understanding whether side effects were normal, the physical implications of treatment, and

Table 5.1: The cancer journey framework, representing the patient-centered cancer experience

	<b>Responsibilities</b> <i>Patient work; health tasks placed on patients</i>	<b>Challenges</b> <i>Barriers to care</i>	<b>Personal Journey</b> <i>The effects of cancer on one's personal, daily life</i>
<b>Screening and Diagnosis</b>	Communicating the disease to others	Information gaps, Emotional impacts, Dealing with others' reactions	Attitude changes, Major life events
<b>Information Seeking</b>	Information filtering and organization, Clinical decisions, Preparation	Overwhelming amount of information, Understanding treatment options	Coping strategies
<b>Acute Care and Treatment</b>	Symptom management, Support management, Compliance, Managing clinical transitions, Financial management	Inability to work, Transportation, Lack of support, Reluctance to ask for help, Unexpected complications	Relationship changes, Responsibilities of daily life, Social behavior changes, Loss of independence, Asserting control, Health milestones, Personal goals
<b>No Evidence of Disease</b>	Continued monitoring, Giving back to the community, Health behavior changes	Worry about recurrence	Survivor identity, Return to normal

preventive cancer measures.

20 of the 31 participants described emotional impacts they dealt with while going through their cancer journey. Participants shared a range of emotions resulting from their cancer diagnoses, such as fear, anger, anxiety, uncertainty and loneliness. Four participants shared that they experienced depression upon diagnosis.

Eleven participants struggled with others' reactions to the diagnosis. Five participants stated that seeing their families' fear was particularly difficult. Further, three participants described awkward or unsupportive reactions from other people, such as sharing "stories of lost loved ones who died from [cancer]." Participants then had to consider not only how to cope with their diagnosis, but also how to handle others' reactions as well.

### *Personal Journey*

Eight participants shared a number of positive attitude changes that resulted from the cancer diagnosis. Examples of these attitude changes include, "living life to the fullest," appreciating everything god has given me," and "appreciating the here and now." Such attitude changes exemplify some of the positive outcomes that emerged from the negative health experiences.

Occasionally, major life events, unrelated to one's cancer journey but occurring during the cancer experience, became integrated with one's reflection of the journey. Fourteen participants discussed significant life events when sharing their cancer experiences. For example, seven participants had family members pass away just prior to or during their cancer treatment. Participants discussed these life events and their cancer experiences interchangeably. While these life events may occur at any of the cancer journey phases, patients must figure out how to manage these events alongside their cancer management on a daily basis. The presence of these events reveals that one's personal health management is not always her or his top priority.

### 5.2.2 Information-seeking

The information-seeking phase describes the time between diagnosis and beginning treatment. During this time, patients often focus on aggressively searching for information about the disease and treatments.

#### *Responsibilities*

Participants often discussed the need to find and filter health information to help them better understand their particular diagnoses and treatment plans. While all participants looked for medical information about cancer, several participants also cautioned against looking online. Some participants recommended limiting Internet searches to only sites recommended by doctors. Thus, patients are responsible for not only finding medical information but filtering the information as well.

All participants also needed to make important clinical decisions regarding their treatment. Patients must make a number of significant decisions, choosing between various surgeries (mastectomy, lumpectomy), treatments (chemotherapy, radiation), and selecting doctors. Each decision has considerable consequences. Several participants shared stories similar to one participant who said, “Having radiation treatment is not an easy thing to do, or a fun thing to do. And there are consequences even though it sounds kind of benign in its own way. So I decided to have a mastectomy [without radiation].”

Fourteen participants also talked about the need to prepare for upcoming treatments. Participants discussed a variety of preparation tasks. Most participants would read about upcoming treatments and organize their calendar with appointment information. A few participants also wrote down questions to ask doctors prior to appointments, and talked to survivors who completed similar treatments about their experiences.

### *Challenges*

In this phase of the journey, patients must independently manage an overwhelming amount of information, often causing additional stress. Three participants highlighted that this stress, and the limited time between diagnosis and treatment, made it difficult to understand their treatment options. These participants stated that they wished they had more time to process this information, which was often provided to them in large cancer binders.

### *Personal Journey*

As participants moved forward in their cancer care, the effects on their daily life became more prominent, forcing patients to directly confront how they would cope with this new health situation. To manage the range of emotions and mental changes, 16 participants discussed a range of coping strategies. Seven participants focused on religion and prayer when they felt stressed. Another six participants emphasized the need to stay preoccupied through work, social events, or online games to stop them from dwelling on the diagnosis and future treatments. While individuals differed in how they handled the diagnosis, many participants strived to find a successful coping mechanism.

#### 5.2.3 Acute care and treatment

A number of treatments are used in breast cancer care, including chemotherapy and radiation. The types, dosages, and frequencies of treatment vary across patients. Nevertheless, commonalities exist as patients work to manage their treatments. This phase of care can be the most time intensive and physically demanding.

### *Responsibilities*

Symptom tracking becomes critical during this phase of care so physicians understand how patients are reacting to their treatments [22]. Participants discussed a range of physical side effects such as pain, bruising, nausea, losing fingernails and hair, and fatigue. Participants

frequently discussed the need to actively manage side effects by keeping nurses informed. Support management also becomes a necessity, as patients must share their health information and updates with their support network. Participants did this in a variety of ways. One participant shared that she delegated responsibilities, asking one person to drive her to and from chemo, and another to help specifically with domestic chores. In addition, treatment compliance becomes one of the most important responsibilities placed on patients in order to ensure effective treatment.

21 participants highlighted the importance of managing clinical transitions as participants completed surgery, began various treatments, and transitioned into post-treatment survivorship. Many participants talked about feeling the most anxious during these transitions. Five participants in particular echoed sentiments that transitions were each a “learning curve,” marked by uncertainty.

Financial management was a significant task for 14 participants, with several stating it was the most difficult and stressful task they faced both during and after treatment. Four participants did not have health insurance to cover the costs of treatments, and five participants did not have a regular source of income. However, even for those participants with a job and insurance, financial management proved very difficult. As one participant stated, “even with insurance, this year has been crippling having to pay the 20% that insurance didn’t cover.” While some participants admitted that they chose to ignore the bills in order to emotionally cope with the financial burden, others stated that they dealt with the burden by looking for grants and other financial resources, or asking for help from family and friends. For example, one participant shared that her family members bought her groceries during active treatment so that she could pay her medical bills.

### *Challenges*

Participants discussed a range of challenges they faced while in treatment, highlighting the diverse needs that arise during this time. Ten participants became physically unable to

work due to extreme fatigue and pain. An inability to work often led to financial stress and reduced social support.

Transportation became a challenge for seven participants, as many lost the ability to drive themselves. Participants marked this inability to drive as a particularly significant change, as they now depended on family and friends to attend treatments.

Social support, while valued by all participants, was not always available. Seven participants recalled moments when they did not have adequate social support. For instance, one participant shared that her worst moments during the cancer journey were “times when you needed family and they were not there to support”.

For nine participants, a reluctance to ask for help occurred in parallel with an increased need for help. For three participants, this reluctance stemmed from not wanting to feel like a burden to others. Another two participants shared that they felt as though they were lucky to have received a treatable diagnosis, and therefore did not wish to draw attention to themselves.

In addition to the expected side effects, thirteen participants also dealt with unexpected health complications. These complications included infections and allergies to medications. Occasionally these complications had serious impacts. For instance, one participant spent a week in the hospital after her blood sugar became dangerously low following a chemotherapy treatment.

### *Personal Journey*

The consequences of cancer treatments on one’s daily life are numerous. Eight participants shared how family relationships changed. For two participants, their children moved closer in order to take care of them. In another situation, a participant was the caregiver for her elderly aunt, but said they swapped roles while she went through cancer treatment. Three participants stated that through the cancer experience they became closer with family members.



Participants also talked about many responsibilities of daily life, which had to be balanced alongside treatment. While not directly related to cancer, these parallel responsibilities became embedded in participants' cancer experiences. For example, the participant who lost her husband just prior to her diagnosis stated, "I was very busy dealing with the details following my husband's death. As executor of his will, I had many responsibilities." Another participant shared that she continued her college studies throughout her diagnosis and treatment. Thus, not only do patients gain a number of new responsibilities as they manage their disease, but they must also balance a variety of ongoing commitments.

Six participants discussed social behavior changes, such as a new focus completing their "bucket lists," making new friends, volunteering, and participating in new social activities. These six participants highlighted the importance of participating in social events to maintain a positive attitude. As one participant, who joined a softball league after her diagnosis, summarized, "The men in the softball league were sweethearts. The sport kept me busy, gave me purpose. You really need a purpose to live."

An increased need for help often contributed to participants' feeling a loss of independence. Six participants shared that they relied on others for a range of tasks, including "mental and financial support." These participants all described this realization as a significant moment of change that at times was difficult to accept. One way participants managed this loss of independence was by purposefully asserting control when possible. Six participants discussed ways in which they asserted their control during treatment. Four participants shared that they decided to make cancer care decisions independently, occasionally opposing doctor or family recommendations.

While many negative consequences can come from a cancer diagnosis, six participants celebrated positive life milestones that occurred during their cancer journey. Finishing treatments served as one commonly discussed health milestone, especially after subsequent tests came back with good results, which as one participant stated, "produced euphoria."

A few participants also shared personal goals that they continued to work towards dur-

ing and after cancer treatment. Many participants discussed wanting to learn to better manage their health and wellness and improve their overall quality of life.

#### 5.2.4 No evidence of disease

Upon completing treatment, patients with non-terminal cancers can reach a point in which no evidence of the disease remains in the body. While patients are considered cured at this phase, continued testing becomes critical to monitor for cancer recurrences. Continued treatments, such as hormone therapy may also be used during this phase.

#### *Responsibilities*

Several participants shared a desire to give back to others as a cancer survivor. Participants felt a need to volunteer or share their knowledge with others once they completed treatment. Nine participants also felt obligated to take better care of their physical wellbeing. Health behavior changes included going to their general physicians more, keeping up to date with health checkups, and being more vigilant with their diets. For one participant, these health behaviors extended to her family as well, as her daughter began getting regular mammograms.

#### *Challenges*

A well-documented challenge people face after a cancer diagnosis is the concern of a recurrence [108]. Participants also described this post-treatment anxiety frequently. Many of the participants expressed feeling this once their active treatment ended. As one participant stated, “I think I will always have fear of a possible recurrence even though tests are positive.”

### *Personal Journey*

Thirteen participants shared different ways in which they embraced this new aspect of their lives after treatment, taking on different cancer identities. Three participants identified as cancer survivors, with one participant sharing that she is now “a big spokesperson for mammograms and checkups.” In contrast, five participants said they felt that cancer was just an obstacle to get through, stating, “this is a bump in the road,” “I refused to be permanently labeled as a cancer survivor,” and “I never really classified myself as a cancer victim.” Understanding these different attitudes toward cancer after treatment may help to provide tailored, ongoing support to survivors.

As participants completed treatment, resuming normal routines became another significant milestone. As the side effects wore off, ten participants shared their excitement about resuming routines such as “eating again” and “being able to drive again”.

### **5.3 Designing across the cancer journey**

The cancer journey framework helps to motivate the design of tools that support patients’ dynamic needs as they move through multiple phases of care. Our participants faced continuous challenges as they transitioned through their care. Many participants struggled with understanding treatment options, preparing for treatments, and managing side effects. They needed support that reached across different phases of care, allowing them to cope with existing challenges as well as prepare for future healthcare changes, which bring new uncertainties.

The framework calls attention to the value of flexible, adaptive platforms, helping connect patients with personalized sets of tools targeted to their individual and changing experiences. Platforms that curate and promote programs and applications based on patients’ personal information and health records can be used to customize health tools to one’s specific cancer journey. Such tools could help patients, providers, or caregivers ensure that

priority needs are covered at each phase of care. For example, providers could find and add financial management tools for newly diagnosed patients with lower socioeconomic status. Resources targeted for survivors after treatment could then surface as patients reach the end of acute care and treatment.

Of course, such health-focused platforms must also consider the personal implications of a cancer diagnosis. I heard repeatedly from the people in this study that they refused to be defined by their cancer diagnosis and many expressed specific strategies in reaffirming existing activities or finding new activities that reflected their true identity. A nuanced design challenge is how to create tools that recognize that cancer invades not just the body, but also many facets of daily life, without redefining all of life as a cancer journey. A possible, yet whimsical, opportunity is a master switch that “turns cancer off” from the computing device when patients need a break and re- integrates cancer information when desired. Such a switch could allow a patient to check their email and calendar without being inundated with cancer-related information.

## **5.4 Discussion**

In this chapter I presented a framework to allow researchers, designers, and healthcare professionals to understand the diversity of factors that comprise a person’s cancer journey. The results of this work highlight the robust range of responsibilities, challenges, and personal factors that patients grapple with while managing their cancer care.

The need for holistic support arises not just from meeting patient needs, but perhaps just as importantly, focuses more broadly on the life of the individual as a whole, moving beyond a narrow focus of illness management. While a single application or technology may not practically be able to address patients’ wide variety of needs, a coordinated system of tools and resources may provide the necessary level of holistic and flexible support that patients need to successfully navigate their cancer journey. Thus technology designers must ensure that patients have access to tools that collectively support their range of needs.

I developed the cancer journey framework to guide this pursuit. One practical method for leveraging this framework may be to aggregate informational resources pertaining to the responsibilities and challenges common in a particular phase of care - a strategy I explore further in the design of MyPath.



## CHAPTER 6

### MYJOURNEY COMPASS: IDENTIFYING OPPORTUNITIES FOR MOBILE TECHNOLOGY TO PROVIDE COMPREHENSIVE SUPPORT

To better understand the opportunities and usage barriers associated with integrating health management tools in patients' lives, I provided breast cancer patients with a mobile, tablet-based health management aid, named My Journey Compass. The My Journey Compass project provides a new model for personal health technologies by incorporating health and non-health uses in a single tool, providing patients with the ability to customize the interface and applications on the tool, and utilizing a strong partnership with an existing healthcare system and local cancer navigation organization throughout the design and deployment.

During the year-long deployment of the MyJourney Compass system, I ran three evaluations of the system. First, I interviewed participants about their use after one month in order to assess how participants viewed the value of the technology and integrated the device into their daily routines. Second, I combined an interview study with an analysis of tablet use logs in order to determine how usage changes in relation to time since diagnosis. Finally, I evaluate participants' usage logs in comparison to their treatment plans, assessing correlations between changes in use and type of treatment. The results of this work reveal both the benefits of using a flexible, customizable approach to the design of health tools, and opportunities to improve upon the design of systems that aim to offer comprehensive support. Thus, this study helps to answer the research question: *What are the critical design goals and technical features for a system that supports patients' health management over time?*

The results of this work offer a number of contributions to the HCI and health informatics communities:

1. I provide a model for, and discuss the benefits of, combining personal and health technologies. 2. I discuss motivating factors that led participants to integrate the technology into their daily lives including customization, mobility, balance of information, and privacy. 3. I discuss the importance of integrating new health management technologies into existing healthcare systems and discuss how such integration strengthened both the research project and the existing healthcare system 4. I describe participants' usage patterns and the insight these patterns provide into the various ways a flexible health tool may support patients' healthcare needs.

## **6.1 Health system partnership**

One goal of this study was to develop a tool that could be supported through the patients' health system. I worked with several types of health professionals throughout the design phase of the My Journey Compass tool, utilizing the expertise of professionals who work with cancer patients daily. The health professionals included oncologists, cancer navigators, breast cancer survivors, the Director of Operations at Harbin. This collaboration ensured that we selected useful and reputable resources for the tablets that were relevant to participants' local cancer care system. For instance, we provided participants with the names and contact information for their doctors and for the navigation organization directly on the tablet. Utilizing the healthcare partners in the tablet design, I developed a tool that could support a broad range of expected breast cancer challenges, while also employing the strengths of the existing health system and local resources (such as the cancer navigation organization).

### 6.1.1 Collaboration with cancer navigators

In addition to using the healthcare partners in the design of the tablet, I also worked with them throughout the deployment of the technology. I believed introducing the project through representatives of the healthcare system would be important in demonstrating to



participants that their healthcare teams supported this tool. I hoped that deploying My Journey Compass in this manner would encourage patient trust in the technology and its informational resources.

Cancer navigators became the key stakeholders responsible for introducing breast cancer patients to My Journey Compass. Using cancer navigators for this purpose was appropriate for several reasons. First, I was already working closely with the navigation organization and had developed close relationships with the navigators. Second, the previous study with the cancer navigators indicated that they could contribute to successful technology deployments due to their close relationships and expertise in working with cancer patients. Finally, navigators meet with patients at the time of their diagnosis, so the introduction of the research fit easily into these existing meetings. Thus, we determined that navigators would introduce the study to patients and present those who would like to participate with their MyJourney Compass tablet.

#### 6.1.2 Creation of education navigator position

In developing the process of introducing the research to patients, we discovered that certain aspects of the project would fall outside of the responsibility and abilities of the current navigators. When patients acquired their tablet, we needed to present them with formal training and a point of contact should problems or questions arise. Since this training would need to occur soon after a patient's diagnosis, the navigators agreed that someone within the navigation organization would best serve these responsibilities. This decision led my collaborators to create a new position for education navigation.

The education navigator was given the responsibility of providing a one to two hour training session for each new participant. In addition to providing an overview of the applications and functionalities on the tablet, the training was important in providing a level of customization not yet seen in mobile health tools. The education navigator was able to talk to patients about their questions, concerns and goals, and to show them how the

tablet could be used to address those specific issues. The education navigator also provided participants with a single point of contact for any technology-specific questions that arose after training.

While this study focuses on the design and patients' use of My Journey Compass, I also note the importance of the healthcare system changing to support the distribution and upkeep of the tablets. Given the scarce resources available to the navigation organization, I value their early adoption of this approach. Introducing participants into the project via the cancer navigators allowed us to be particularly sensitive to participants' needs. The weeks following a cancer diagnosis can be a difficult and emotional period. Navigators are experts at working with patients during these arduous times, building close relationships with patients, and providing constant support. By having navigators introduce the tablet and train patients, I was able to utilize the navigators' expertise, provide technology support to patients through an organization they already knew, and avoid overwhelming participants by asking them to speak with researchers so early in their cancer journey.

#### 6.1.3 System design

The goal for this project was to develop a health management tool that patients could easily embed into their regular daily routines. Through the design process with the healthcare partners, I selected a suite of applications, PDF informational resources, and websites deemed useful for breast cancer patients (Table 6.1.3). I deployed a seven-inch Android tablet (the Nexus 7) for two reasons: the portability of the device allows patients to have it with them all the time, supporting health information management away from the home; and stock android tablets provided a clean user experience that gave patients the ability to easily customize and personalize their tablet experience. I encouraged patients to add or delete applications of their choosing. An overview of the MyJourney Compass layout and features can be found in Appendix A.

Table 6.1: List of resources included on the My Journey Compass tablets

<p><b>PDFs</b></p> <p>2011-2012 Breast Cancer Facts and Figures, After Diagnosis: A Guide for Patients and Families, Breast Cancer Detailed Guide, Breast Cancer Dictionary, Breast Cancer Overview, Breast Reconstruction After Mastectomy, Exercises After Breast Surgery, Fatigue in People with Cancer, Inflammatory Breast Cancer, Lymphedema: What Every Woman with Breast Cancer Should Know, NCCN Guidelines for Patients, Nutrition for the Person with Cancer During Treatment: A Guide for Patients and Families, Sexuality for the Woman with Cancer, Snapshot of Breast Cancer Surgery Choices for Women with Breast Cancer, Survivorship Nutrition Guide, Talking with Your Doctor, Understanding Chemotherapy: A Guide for Patients and Families, Understanding Radiation Therapy: A Guide for Patients and Families, What You Need to Know about Breast Cancer, Your Guide to the Pathology Report</p>
<p><b>Applications</b></p> <p>Calendar, Cancer.net, Caring Bridge, Contacts Widgets, Dictionary, Keep (note taker), My Fitness Pal, Nutrition Facts, Paced Breathing, Personal Email, Wifi Finder, Relieve Stress</p>
<p><b>Bookmarks</b></p> <p>ACS:Breast Cancer, Herceptin 2, BreastCancer.org, National Breast Cancer Foundation</p>
<p><b>Entertainment</b></p> <p>Facebook, Pinterest, YouTube, Pandora, Flipboard, Angry Birds, Wikipedia, Google Play</p>
<p><b>Cancer Navigation Resources</b></p> <p>Cancer Navigators Brochure, Caring for the Caregiver, Sustainable Wellness Brochure, Retreat Brochure 2012, Why You Should Visit Cancer Navigators</p>

## **6.2 Deployment**

### 6.2.1 Recruitment

Participants were recruited into the study through the cancer navigator's organization. Recruitment occurred immediately after patients' first treatment consultation with their oncologist, as navigators are typically present at this meeting. Patients received the tablet from their cancer navigators and were encouraged to use it any way they wished, with no restrictions. Upon receiving the tablet, participants set up a training session with the education navigator, which typically occurred one to two weeks following the initial consultation.

### 6.2.2 Participants

36 patients diagnosed with breast cancer (Stage 0 through 3) enrolled in the MyJourney Compass deployment study between August 2013 and March 2014 through the Rome health system. 35 participants were female and one male. Participant ages ranged from 24 to 80 years old ( $M=60$ ). Participants on average had the tablet for 310 days, with a minimum of 170 days and maximum of 365 days. 36 patients declined to participate (50%), often because they felt overwhelmed by the diagnosis.

### 6.2.3 Data Collection and Analysis

#### *Initial Interview*

After approximately one month of tablet usage, I conducted semi-structured interviews with participants to explore their initial tablet usage. Upon completion of the interviews, I used an iterative inductive analysis to uncover themes around usage patterns and motivations for technology adoption. I transcribed the interviews and segments of the transcripts were clustered to further develop these findings. Members of the research team then reviewed the segment clusters and verified each of the themes.

During the initial set of interviews I met with twelve breast cancer patients, eleven female, each of whom had possessed the tablet for at least one month. Four of the participants were in the middle of their treatment at the time of deployment; the remainder received the tablet upon diagnosis or as part of their first appointment with general surgery. Participant ages ranged from 39 to 80.

#### 6.2.4 Usage Logs and Follow up Interviews

I analyzed participants' use of the technology from the time they received the tablet until September 2014. Each tablet included an application tracker that logged the application name, the date and time the application was opened, and the duration of time for which the application was used. While I logged the launching and closing of individual applications, I did not track activity within applications, such as search terms or social media posts. To analyze the data, each activity was categorized as being either health or non-health use, based on the application being used. Applications added by the research and healthcare team, such as the included PDF information, MyFitnessPal, and Nutrition Facts were categorized as health applications, while entertainment and religious applications were considered non-health. Usage was then partitioned by user, by day, and mapped chronologically to investigate changing use patterns.

In order to gain additional context around the usage logs, I interviewed participants about their healthcare journeys and tablet usage. I interviewed 13 participants who were near the end of or had already completed radiation and/or chemotherapy treatment. These interviews expand on the results of the initial interview study, helping to provide insight into how personal and clinical factors influence technology usage behaviors. Using an iterative thematic analysis, I examined the data with a specific interest in understanding how participants used the tablet throughout treatment and into survivorship.

### 6.2.5 Patient Treatment Data

In addition to tablet usage logs, participants were also asked to allow access to their medical information, including diagnosis and cancer treatment start and end dates (including surgery, chemotherapy, radiation, and hormone therapy).

I received treatment information for 17 participants. While 36 participants enrolled in the study, several participants did not have health records accessible to the research team. Health records were not available for participants who opted to receive treatment outside of the cancer clinic where the technology was deployed.

All participants were diagnosed with stage I-III breast cancer. Participants' cancer treatments may be categorized into four general paths. Eight participants had a lumpectomy, followed by radiation and five years of hormone therapy. Five participants had a lumpectomy followed by chemotherapy and radiation and five subsequent years of hormone therapy. Three participants had a mastectomy, followed by chemotherapy and five years of hormone therapy. Finally, one participant had a mastectomy followed directly by five years of hormone therapy.

## **6.3 Findings**

Collectively, 36 participants used the tablet for 2,316 hours. On average, participants used the tablets for 2.6 hours/week. We captured 40,884 distinct instances of application use, across 239 unique applications. In this section I describe the usage habits of the participants. First, I present the most common reasons participants utilized the tablets. I then discuss factors that motivated participants to adopt the technology. I then describe three patterns of use found through an analysis of usage logs. Finally, I show how a comparison of usage logs to patients' treatment plans reveals how usage changed with respect to treatment.

### 6.3.1 Tablet Uses

In this section I describe the usage habits of the participants, which were evaluated using the initial interview data with 12 participants. First, I present the most common ways participants utilized the tablets. I then discuss factors that motivated participants to adopt the technology.

Nine of the twelve participants used the tablet regularly, employing both preloaded resources as well as applications added to the tablet by the participants themselves. Three of the participants reported low usage of My Journey Compass. These participants described having an initial interest in the tablet upon first acquiring it, but described no subsequent use.

#### *Relaxation and Entertainment Tool*

One of the most common, yet unexpected, uses of My Journey Compass was as a relaxation and escape tool. Patients used Pandora, online books, preloaded stress relief tools, and a variety of downloaded games to relax. Eight participants reported using the tool to help them alleviate anxiety:

*“This is something you can just sit and do. And it takes away some of the anxiety. It keeps you from thinking What if? What could? Should I?” P8*

Although using the tablet to relax was a common theme, the times when participants would use the tool as a calming mechanism varied. Two participants discussed taking the tablet to chemo to help them pass the time:

*“One of the best things about it was being able to take it to chemo and have it and plug in my earphones and if I wanted to listen to music or if I wanted to read a book or whatever it is. It just made the whole thing a lot more relaxed and easier.” P6*

Using the tablet to relax during chemotherapy not only highlights the importance of providing patients with mobile tools, but also suggests that treatment may impact patterns of health technology use. In addition to chemotherapy, three patients discussed using the

tablet while waiting in doctor's office in order to pass the time:

*"In the doctor's office, instead of just waiting there with nothing to do I would get on there and check email or go on the Internet." P3*

Participants discussed various ways in which they could relax using the tablet. Many of the relaxation tools (such as the online books and games) did not come with the original tablet setup, but rather were applications participants downloaded for themselves. Support for relaxation is one of the most significant ways in which providing a flexible and customizable health tool for patients was useful for them. If patients were solely provided the applications included in the MyJourney Compass suite, this usage pattern may have never emerged, and yet it was a pattern adopted by nearly all of the participants who used the tablet during treatment. Allowing patients to customize other health management tools may help researchers identify additional unforeseen benefits of such tools.

### *Personal Uses*

Even though participants received the tablet from the health system as a health tool, they were encouraged to use the device in any way that they wished, without restrictions. This flexibility led seven of the participants to engage with the device for personal reasons above and beyond their use of the tablet as a health tool. They discussed numerous ways in which they used the tablet in daily life:

*"I used it at church one time, to take notes from the pastor, and it picked up his voice."*

*P1*

*"I've done YouTube, I have Flipboard, I use that a great bit. Oh I have to show you [a picture of] my grandson!" P8*

While participants already used the tablet in a wide variety of personal ways, some discussed new ways they would want to use the tablet in the future. For example, one of the participants is a music teacher, and thought the tablet could be used to record her student choir once classes resumed in the fall. With such a wide range of personal uses and



potential future applications, the role the tool plays in participants' lives can vary over time. Personal uses may help alleviate the novelty effect of the technology and keep participants engaged.

### *Tool for Supporting Others*

Although less common, two participants shared stories in which they accessed the tablet to help others with their health needs. While this did not come up in conversations frequently, these powerful stories show the importance of making mobile health technologies available to those with chronic diseases. The first participant who mentioned helping others through the tablet used the nutrition application to support family members with diabetes:

*“Diabetes is strong in my family [The nutrition application] has a list of food with no sugar, low carbs, you know. I have a niece that’s diabetic. And I said ‘look sweetie, when you go to the store look at what you can get, what you can’t get.’ She said, ‘I didn’t know that information was out there aunty.’” P1*

In the second occurrence, a participant talked about her best friend, who was diagnosed with breast cancer two weeks before the participant received her own diagnosis. The participant was able to use share the resources on the tablet with her friend:

*“I have a best friend diagnosed two weeks before I was, my best friend she’ll have questions and I’ll say ‘well let me check that.’” P8*

These uses begin to show a new way in which health tools can enhance empowerment and strengthen a social support network. By being informed and having easy access to resources, participants were able not only to use the tools for their own health, but also use the tool to help guide others through their own health challenges.

### *Organization and Memory Aid*

In talking with participants, I found several uses similar to those presented in other studies examining patients' use of mobile health tools. For instance, seven of the participants used

the tablet as an organization and memory aid, primarily by calendaring and note taking. Other studies working with breast cancer patients also noted participants' desires to be able to quickly and easily capture notes, appointments, and other important information with mobile tools [109], especially since forgetting important medical information is a significant problem for cancer patients [36]. Participants discussed being more on time to, and informed during, doctor appointments. This result helps demonstrate that mobile health technologies may be able to directly impact the quality of care provided to cancer patients by providing important reminders for patients that can increase attendance at medical appointments, treatment adherence, and other health behaviors [8].

#### *Communication Support with Doctors*

Another benefit of the tablet discussed by six participants was supporting patient-doctor communication both during and after appointments. Other studies providing cancer patients with the ability to electronically share health information with clinicians found improvements with patient-clinician communication, with patients sharing more information with the clinicians [110, 100]. The Healthweaver project also found improvements in patient-doctor communication as the mobile technology allowed participants to answer clinical calls while away from home and provide more accurate health information during clinical visits [61, 76].

In this study, participants specifically discussed feeling prepared and confident when speaking with their health providers, demonstrating the empowering impact a health tool can have for patients. Many participants also discussed feeling less worried after an appointment because they were able to review parts of discussion they had recorded that they were unable to process or understand during the actual conversation.

### *Enhancing Support System Communication*

Our formative interviews with patients, as well as prior studies [111, 8], found the importance of social support for cancer patients. Seven participants discussed using MyJourney Compass to communicate with their family and friends. Several participants mentioned that being asked questions they could not answer triggered them to use the PDF resources. In addition, participants discussed recording doctor appointments and sharing the audio with caregivers who could not attend the appointment. Using the tablet in this manner indicates that the technology may have lasting impact on users. Facilitating social support can play a significant role in healthy behavior change [112] and can lead to improved health measures, such as lower hospital readmission rates [8].

#### 6.3.2 Factors Motivating Adoption

To more fully understand whether this technology could improve the cancer care experience for breast cancer patients, I examined participants' motivations for adoption. I found that certain system design features significantly influenced the usability and utility of the tablet. These results used data from both sets of interviews and tablet usage logs.

### *Customization*

A unique aspect of this study was the use of an open platform that patients could personalize. In order to make the technology customizable, I provided features, Google Play being one, which would allow for exploration and discovery of new applications. Patients were not specifically trained on using this application, but they were told that they could use the tablet however they liked. Thirty-five participants added applications to their tablets, on average adding nine applications (ranging from 0 to 32). In total, 178 unique applications were added to the tablets. Entertainment applications including Candy Crush and Amazon Kindle, as well as the Bible were the most commonly added applications, added by 10, 9, and 7 participants respectively.

Device customization enabled new and unexpected uses of My Journey Compass to emerge. The ability to add applications proved valuable to many participants as they could add personally meaningful resources. For example, several participants shared that they added photographs of family members onto the tablet. Religious applications were also frequently added. 13 participants added 16 different religious applications, such as the Bible and Gospel Library. This type of unexpected outcome reinforces the importance of allowing patients to modify their health management tools. The addition of religious and other personal applications demonstrate how technologies such as the My Journey Compass tablet may assist patients not only through their clinical treatments, but also by supporting their personal well-being. Existing literature highlights the number of psychosocial challenges cancer patients face and call for research to focus on improving patients' psychological wellbeing [4]. The use of customizable platforms provides one way in which technological interventions may support patients' clinical and emotional needs. Further, researchers may learn a great deal about participants' values and needs by employing the use of customizable tools.

Interestingly, while patients added entertainment and religious applications, no participant added cancer specific applications to the tablets. However, the interviews revealed that entertainment and other non-health applications served underlying and unexpected health purposes. Several participants discussed using games, books, and music as a way to stay calm during the stress of receiving chemotherapy treatments and to improve their emotional wellbeing during particularly stressful moments. In addition, one participant revealed that she used the tablet to support her transition to an all vegan diet, often relying on YouTube videos for recipe ideas. Social media became an additional health platform, with one participant sharing:

*"I used [Facebook] as a teaching tool. What I found I would share with other people and refer them to the websites I would use." - P16*

These examples demonstrate the ability for personal resources, such as online games,

YouTube, and Facebook, to serve underlying health purposes, demonstrating the importance of expanding our view of what constitutes a health resource.

Another trend I found across all of the participants who used the technology during treatment was that health was always a gateway into personal use and customization. No participant adopted the tablet as a personal device before using it as a health tool. This finding could be important for keeping users engaged with health tools once the novelty of the health device fades. By providing a tool that shifts between a health and personal device, participants may be, over the long term, more likely to return to using the tool for health purposes should the need arise. We expect this behavior might occur as a result of participants continuing to use the tool and thus would still have the technology readily available and integrated into their daily lives.

Designing for customization in health management tools allows patients to modify the tool freely as new challenges arise in their lives and in their treatment. It also affords researchers the ability to gain a deeper understanding of the needs of breast cancer patients by monitoring usage of customizable tools. The ability to modify technology allows MyJourney Compass to remain relevant and useful to patients as new healthcare applications and resources become available to patients over the course of their treatment. Further, the personalized nature of the tool may allow it to be useful upon completion of treatment, affording patients the ability to revert to using it as a health tool should the need arise.

### *Mobility*

Participants used My Journey Compass in a large variety of locations. Being able to take the technology to chemotherapy helped the participants relax during treatment. The tablet provided a mechanism for participants to easily capture and retrieve questions for their doctors, thus enhancing the quality of their discussions and improving both the participants and providers satisfaction with the experience. Several participants who used the tablet during travel felt more confident by simply having their doctors' information readily avail-

able. These particular uses begin to show a relation between tablet usage and treatment. Through a better understanding of how treatments impact health management technology usage, tools may be designed to support patients through specific care plans.

Coming into this project I knew from my previous work and related studies that mobility would be an important element for helping breast cancer patients. I was surprised to find the broad range of ways mobility initiated increased usage. The portability of the tablet proved important for helping participants ease their mind during treatments and empowering participants to travel.

### *Balance of Information*

All of the participants who used the tablet at some point used it to investigate health information. The tablet allowed for efficient information retrieval for patients who engaged with the preloaded resources. Because cancer affects people in different ways, one of the most common information seeking activities was looking up side effects and impacts of treatment, especially for chemotherapy and radiation. When discussing with participants their preferred resources for information seeking, I found they most frequently used the PDF resources that came preloaded on the tablet. Participants discussed trusting these resources more than information they could find online because the PDFs came directly from their health providers.

When speaking with participants about why they first began to use the tablet, the desire for as much information as possible without feeling overwhelmed, motivated participants to use the tablet. Typical resources for breast cancer patients come in the form of loose papers and pamphlets or large binders. Many participants described sorting through the vast amount of paper-based information as an overwhelming and negative experience:

*“When you first hear that diagnosis you are overwhelmed [The doctors] are great but they are all the time just handing you, especially for your first couple appointments, just handing you all kinds of paper and information. You go home with this bag of stuff and*

*you're like 'I don't even want to look at this right now.'*" P6

*"I had to compartmentalize everything because I could see I was going to be overload. And when you do that I think your whole positive attitude just crumbles."* P9

While many participants agreed that receiving such a large amount of information was overwhelming, many of these same patients also discussed a need for more information to help them cope with their diagnosis:

*"When you first get diagnosed you want to find as much information as you can, or I did the more information you get, it helps you through it."* P2

*"I was thrown quite a few resources but at the same time there's no impact particularly. You get so much that the knowledge is hard to assimilate I felt a little on my own."* P12

The tablet improved the presentation of information by sorting informational resources into labeled PDF files. This organizational strategy helped participants easily find information when they wanted it, but the resources were also easy to ignore when they were not needed. One patient compared the tablet to the paper resources and described how the tablet helped her find specific health information:

*"In the beginning you get all this information. Every doctor gives you information. To go through it and read all that is exhausting but for some reason when you pull it up here it's not You find what it is you really want to know and you pull that up, so you don't have to weed through a lot of other stuff. It's quick, and that's very helpful for me."* P8

By providing participants with information that was easy to find, organize, and manage, the tablet successfully engaged participants. This initial use often led to further exploration of the tablet features and adoption of the technology. Researchers and designers of future health technologies are faced with the challenge of providing patients with a robust set of resources that are beneficial but not overwhelming.

## *Privacy*

In the interviews, several participants discussed their desire to keep their diagnosis private, mainly to avoid the added attention a cancer diagnosis brings. Two participants specifically discussed how people's reactions impacted them negatively:

*"I became known as the woman with four children and a husband with brain cancer. I worked a long time to get that behind me and just be me. And then we had this [breast cancer diagnosis]." P18*

*"To be real honest with you there are not a whole ton of people that have shared the fact that I even have cancer. Most people's response is 'oh my god' but I'm not one of those 'oh my god' people. That just makes me feel strange when they do that, so I just won't tell them." P7*

Although I had not focused on the issue of privacy during the design of the tablet, I found the technology helped the participants maintain greater discretion than was initially feasible without the tablet:

*"You're sitting in an office and people know why you're there. Even if it's the general surgeon they know why you're there because you have the big cancer folder. So this is great because it's discreet." P9*

I found that privacy greatly contributed to tablet adoption. Participants were motivated to carry the tablet because the technology allowed them to bring their medical resources to public areas while maintaining discretion.

## *Factors Influencing Low Adoption and Usage*

Three of our participants in the interview study reported low tablet usage. I define low usage as essentially ignoring or forgetting about the tablet with the exception of some initial browsing upon first acquiring the device. Through discussions with these three participants, I found each individual had a unique attribute that lessened their need for a mobile health tool. One of the participants had already battled breast cancer once and felt she understood



much of the health information. The second participant worked full time as a nurse and felt she also had less of a need for the medical resources on the tablet. Since the information resources served as one of the key initial motivators for adopting the system, I would expect a participant with a lower need for information to become less engaged in the technology.

For the final participant, many factors may have contributed to the low usage. The participant already owned and carried many portable technologies, including an iPad, a Nook, and a smartphone, so the My Journey Compass suite offered few additional portability features that the patient found attractive. In addition, this participant was the sole man in the study and he discussed how the health information resources were less relevant to his situation:

*“[Being a man] made finding information specific for me more challenging. There’s plenty of information out there about breast cancer, but for men it’s more limited. Examples of men who have had breast cancer would have been helpful.” P12*

Thus, each for the three participants who did not adopt the technology reported that the technology, as an informational tool, was less relevant to their particular needs. Future research could explore how to better support patients with recurrent diagnoses, high levels of medical knowledge, and unique populations such as men in the case of breast cancer.

#### *Frequent Computer Users*

One unexpected outcome came from participants who already used computers in their daily work schedule. Although many of them did utilize the tool, participants also revealed one significant reason they did not use the tool more often:

*“I sit in front of a computer all day and when I get home that’s probably the last thing I want to do is turn on another computer.” P2*

*“I use a laptop all day at work, so I don’t really want to be back on it. I get overdone with electronics.” P3*

I was surprised to find that lower adoption of the technology occurred amongst workers who have already adopted technology into their lives and have high digital literacy. This

finding presents a new set of challenges for those developing mobile health tools. How do we design health tools that do not feel like just another screen to stare at as our world continues to become filled with technology? Our system attempts to provide one potential solution, by combining health with a personal tool, but even this may not be enough.

#### *Low Technical Literacy*

Surprisingly, I found that self-perceived low technological literacy did not constrain technology usage or adoption. Many people described themselves as low-tech users and yet used the tablet frequently.

*“I’m old, sometimes you have to run me through it two or three times.” P1*

This same participant was one of the most frequent users of My Journey Compass. She discussed using the tablet in a variety of ways including calendaring, looking up nutrition facts, and shopping online. This may be in part due to the assistance of the navigators, who provided training tailored to participants’ needs and interests and served as technology support.

### 6.3.3 Use of MyJourney Compass Over Time

In examining how each participant’s tablet usage changed over the course of their cancer journey, I found three common usage patterns emerge. Four participants used the tablet including the health resources regularly, with fewer than 2 weeks between uses (figure 6.1). Twelve participants used the tablets and health resources periodically, with frequent use for several weeks followed by several weeks of no use (figure 6.2). The most common pattern, seen across 17 participants, consisted of regular use of the tablet with sporadic usage of the health resources (figure 6.3). In each of these figures the blue dots indicate days that the participant used the tablet, the red dots indicate days when the participant used the health resources on the tablet, and the grey bars indicate the total length of time that participants had the tablet at the time of analysis.

To better understand what led to these different patterns, I asked participants to reflect

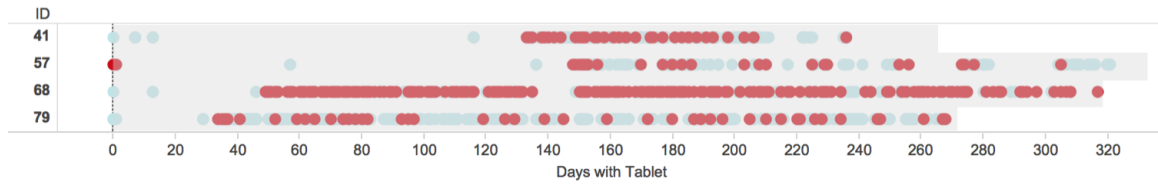


Figure 6.1: Usage data for the four participants who used both the tablet (shown in red) and health resources (highlighted in blue) regularly

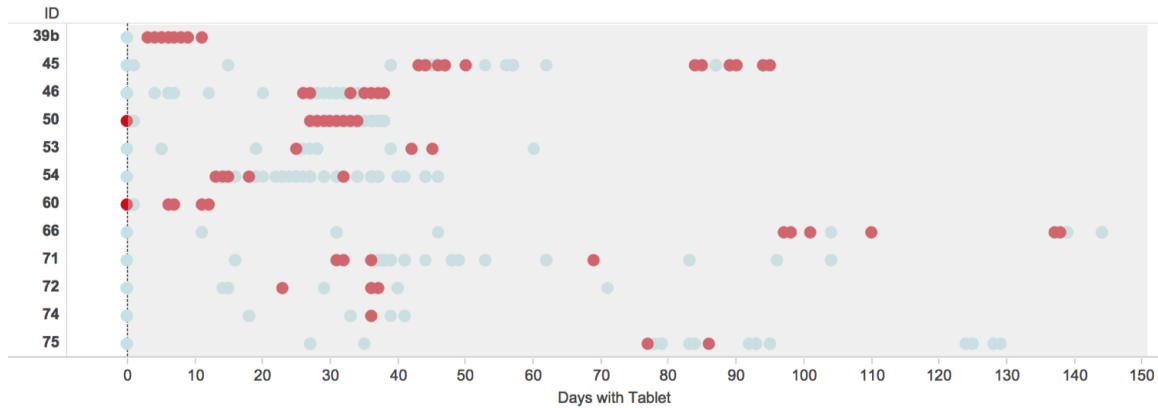


Figure 6.2: Usage data for the twelve participants who used both the tablet (shown in red) and health resources (highlighted in blue) infrequently

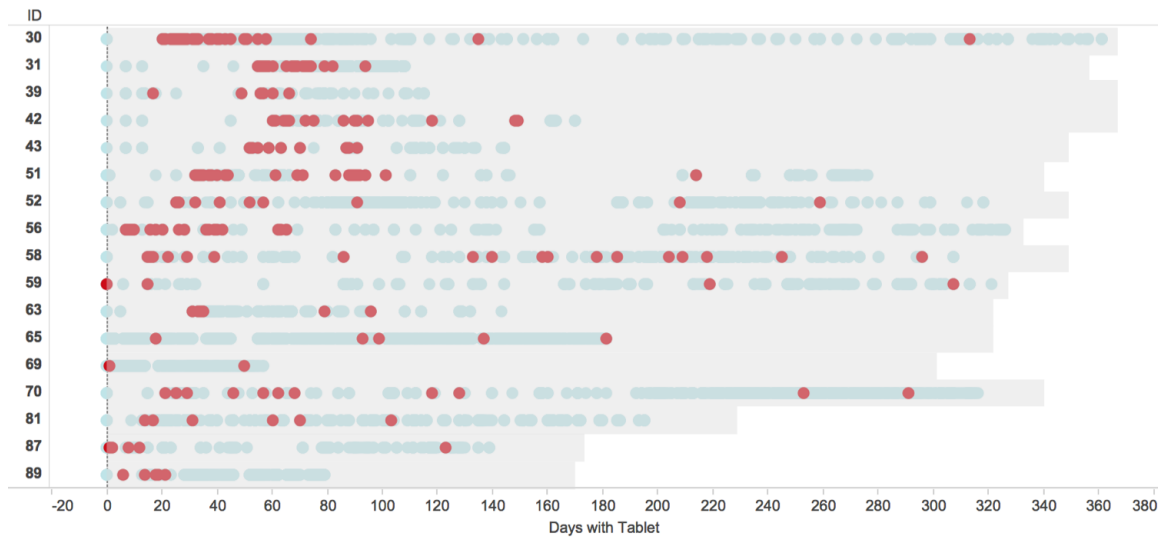


Figure 6.3: Usage data for the 17 participants who used the tablet (shown in red) regularly and the health resources (highlighted in blue) sporadically

on their tablet usage. The post-treatment interviews, paired with the tablet usage logs, validate my initial hypothesis that integrating health and non-health resources would encourage

participants to utilize and return to the health resources when needed. One participant described how she continued to use the tablet for personal reasons once her treatment was complete, but returned to use the health resources on multiple occasions to look up information for others. She used the tablet to look up information about her friend's Melanoma diagnosis and to help her husband prior to his open-heart surgery. Another participant shared that once her treatment finished she stopped using cancer specific applications, as she wanted to focus on her future and more positive aspects of her life. However, she also stated that she would expect to use the tablet's health resources if her clinical treatment plan changed:

*"I'm going to use [the tablet] more for other things than research on cancer stuff. Unless they say 'you have to do a new treatment', then I'll go and research that."*

This trend in which participants utilized health resources when needed because of their engagement with the device points to the ability for the combination of health and non-health resources to encourage greater use of the health tools. The experiences of these participants highlight the need to consider how health resources may be better personalized and seamlessly integrated into people's daily lives through tools that encourage daily use for health and non-health purposes.

#### 6.3.4 Use During Treatments

In addition to understanding how participants' use of the tablets changed over time, I evaluated how usage changed in comparison to treatment dates. This is an important comparison as the types of treatment can impact the challenges patients encounter.

In this analysis I compare participants' use of the tablets and health information at various points in their treatment. To account for variations in treatment times across participants, all results were computed using average weekly use durations, in which I aggregated data into seven day groupings and identified each grouping by when it occurred in a patients' treatment plan (before treatment, during treatment, etc). Of course, many ways exist

to aggregate usage data, thus supporting analysis at different levels of granularity. I used seven-day groupings to account for the significant variation that occurs across individual days. Cubed-root transformations were applied to normalize variables. I indicate in the results when data was normalized.  $P < 0.05$  was considered to indicate a significant difference. Cohen's  $d$  was calculated to determine effect sizes for paired samples  $t$ -tests. For sign tests, PSdep was calculated to estimate effect size [113]. Three of the 36 participants did not use the tablets after training and were excluded from this analysis.

To better understand how tablet usage changed as participants progressed in their cancer treatments I present results pertaining to four research questions:

1. How do participants' use of the health information provided on the tablet change after beginning treatment?
2. How do participants' use of the health information provided on the tablet change during transition weeks?
3. Are particular cancer treatments associated with increased use of health information resources on the tablet?

*How do participants' use of the health information provided on the tablet change after beginning treatment?*

When assessing how participants' use of health information changed with respect to treatment, I first examined how participants' usage changed once they began their first treatment, including chemotherapy or radiation. Beginning these treatments often places new responsibilities on patients as they must organize travel to treatment sessions and begin to manage side effects. Although these changes to daily life may lead to health resources becoming more valuable towards supporting one's self-management, literature has shown that patients often aggressively seek out health information prior to beginning treatment [27]. Therefore, I hypothesized that participants' use of health resources will decrease once treatment begins.

For this analysis I calculated participants' average weekly usage before beginning treatment and during radiation and chemotherapy treatments. The left graph in figure 6.4

shows participants' average weekly use of health resources before treatment (Mdn=5.07 min/week, M=14.37, SD=17.44) compared to the average weekly use of health resources during treatment (Mdn = 0.64 min/week, M = 1.35, SD = 2.26). A paired samples t-test of the normalized data was used to compare changes in use before and after treatment. Participants' average weekly use of health resources was significantly higher before beginning treatment (M=1.90, SD=1.17) as compared to the average weekly use during treatment (M=.77, SD=.59) ( $t(16)=3.627$ ,  $p=.002$ ,  $d=.88$ ).

As participants' use of health resources declined once treatment began, I anticipated that the tablet system overall would become less useful to participants. Thus, my second hypothesis was that participants' use of the tablet devices would also decrease once treatment began. The graph on the right of figure 6.4 shows participants' average weekly use of the technology before treatment (Mdn=75.10 min/week, M=212.51, SD=225.35), and during treatment (Mdn=69.67 min/week, M=107.40, SD=119.42). The paired samples t-test of the normalized data indicated there was no significant change in use of the tablets once participants began treatment ( $t(16)=-.941$ ,  $p=.361$ ,  $d=.23$ ).

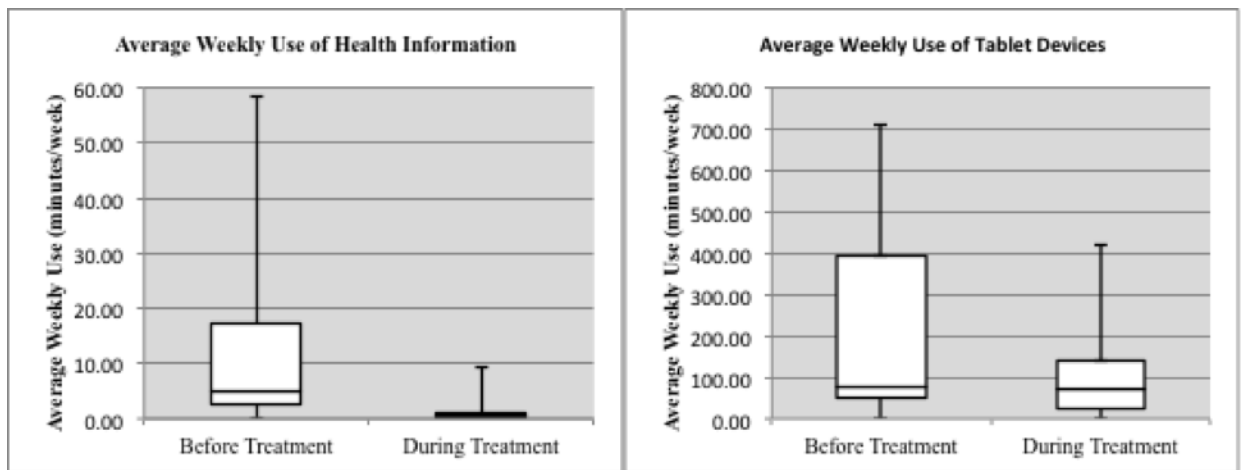


Figure 6.4: Participants' average weekly use of health information and tablet devices before and during treatment.

*How do participants' use of the health information provided on the tablet change during treatment transitions?*

To explore use of the tablet system during transitions, I defined a transition week as the date a participant began a new treatment (specifically chemotherapy, radiation, and hormone therapy) +/- 3 days. I then compared use during these weeks to participants' average weekly usage of the tablet system during non-transition periods. My hypothesis regarding changes in use during transitions was that participants would show a higher average weekly use of both health information and the tablet devices during transition weeks, due to the uncertainty patients may experience during these changes to daily life. The left side of figure 3 shows participant's average weekly use of health resources during the study, excluding transition weeks (Mdn = 3.03 min/week, M=3.52, SD=3.08), compared to the average weekly use of health resources during transitions (Mdn=0, M=1.31, SD=2.11). The data was not easily normalized so a sign test was used to test the hypothesis. The average weekly use of health resources during transitions was significantly lower than the average weekly use of health resources during non-transition periods ( $p=.049$ ,  $PS_{dep}=.76$ ). The right side of figure 6.5 shows each participant's average weekly use of the tablets during the study, excluding transition weeks (Mdn=68.26 min/week, M=100.56, SD=80.81), compared to the average weekly use of the tablets during transitions (Mdn=67.53, M=89.04, SD=82.05). For tablet use, a paired samples t-test on the normalized data indicated that the decrease in use during transitions (M=3.69, SD=1.96) as compared to non-transition periods (M=4.30, SD=1.27) was not significant ( $t(16)=1.751$ ,  $p=.099$ ,  $d=.42$ ).

*Are particular cancer treatments associated with increased use of health information resources on the tablet?*

While my assessment has demonstrated how participants' tablet usage changed during treatment and transition periods, I also wished to examine whether a specific type of treatment was associated with higher technology usage. I created two dichotomous vari-

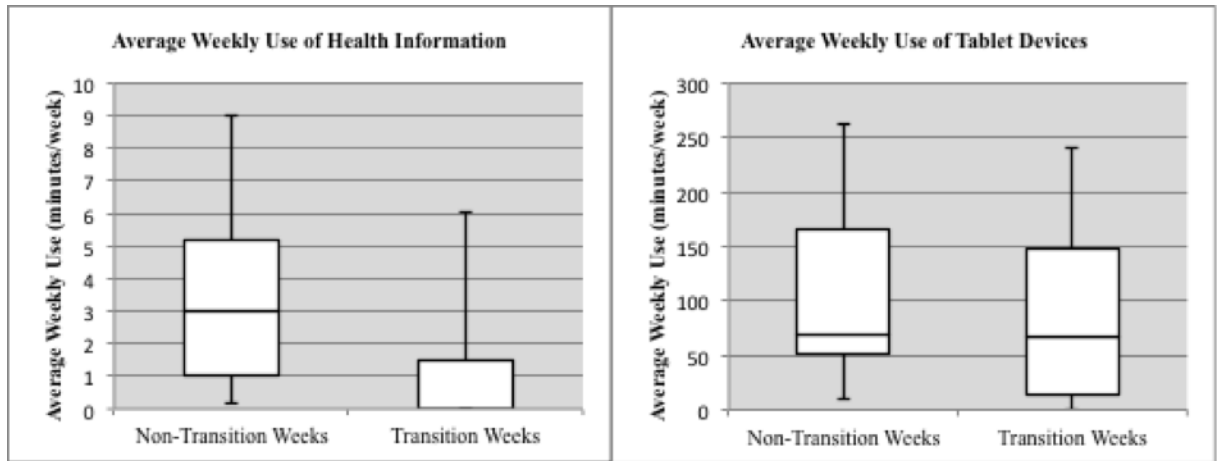


Figure 6.5: Participants' average weekly use of health information and tablet devices during transition and non-transition weeks.

ables, one to indicate whether a participant received chemotherapy and a second to indicate whether a participant received radiation. I first evaluated the correlation between treatment type and overall health information usage. For overall health information usage, I categorized participants into a high health resource usage group and a low health resource usage group that was based on average weekly health usage and split along the median. Two chi-square tests of independence were performed to examine the association between treatment and health resource usage. We repeated this method for overall tablet usage, health information and tablet use before treatment, and health information and tablet use during treatment. The results of these chi-square tests did not suggest any correlation between treatment type and tablet use. Studies with larger sample sizes may help validate these findings.

#### 6.4 Implications for design

MyJourney Compass afforded participants the ability to engage with their health, their health providers, and their support networks by supporting a wide a variety of uses. This work extends existing studies of technology for cancer patients by exploring how patients adopt and utilize a customizable mobile tool for health and non-health purposes that is



integrated into their existing health care system. The study contributes a set of findings that enhance our knowledge of how breast cancer patients may be supported by technology.

#### 6.4.1 Integrating health and non-health resources encourage participants to return to health resources when needed.

As demonstrated through the My Journey Compass usage patterns, participants typically used the tablets for a variety of purposes, returning to health resources when needed. Changes in treatments, new health issues, and the goal of answering others' health questions all motivated this return to using health-specific applications. I found that by providing a tool that supported participant's holistic needs and interests, participants opted to use the technology regularly, affording an easy return to health resources when necessary.

#### 6.4.2 Customizable tools reveal insight into patients' goals and values.

Another finding from the My Journey Compass deployment is that customizable tools can provide significant insight into patients' goals and values. Patients' use of games during chemotherapy and the addition of religious applications highlight the importance participants placed on emotional wellbeing throughout their cancer treatments. This customization can help reveal unintended benefits of health tools, and provide strategies for improving patient engagement. These insights regarding patient's personal goals and values may prove particularly valuable for researchers and providers who wish to develop holistic healthcare innovations.

#### 6.4.3 We must expand our definition of health resources.

My interviews with participants revealed surprising ways in which applications that are not typically considered health-related in actuality supported participants' health and wellbeing. The use of games to reduce stress, YouTube to find recipes, and Facebook to share health information with friends and families all exemplify this finding. These examples

suggest that valuable health uses may be found in a broader array of tools and resources than typically examined. While many tools such as PHRs focus specifically on medical care, to fully understand the opportunities for technologies to support and empower patients we need to broaden our scope and examine how patients utilize technology more generally to support their health and wellbeing. By doing so, we may gain a deeper understanding of how society integrates health into their daily lives and how such technological integration may be improved in the future.

#### 6.4.4 Future research ought to consider novel strategies for supporting treatment transitions

While participants were able to share many ways in which the MyJourney Compass tablets supported their health management, a review of the usage logs compared to treatment dates revealed an important gap in system use. I found that the tablets were seldom used to support treatment transitions. The concern with this usage pattern is that a large amount of information is available to cancer patients upon diagnosis, and an inherent conflict exists between patients' desire for information and inability to manage this large body of information. When provided with an abundance of health information, individuals easily become overwhelmed, have challenges recalling or using the information, and experience a decline in psychosocial wellbeing [29, 3]. Our own participants echoed these challenges, sharing that absorbing such broad information in a concentrated timeframe can be overwhelming and hinder the effectiveness of such information. Frameworks within cognitive psychology may offer important insights for overcoming information overload. For example, distributed practice, which came out of psychology research on memory, suggests that short repeated study sessions is a more effective method for learning and information recall compared to longer sessions [114]. This phenomenon suggests that the existing information seeking phase, in which patients aggressively search for information over a short period of time, may be inhibiting patients' ability to learn about their health or recall the information later in the cancer journey when it may be the most useful.

Adaptive health information systems may offer one useful tool for encouraging distributed use of health resources. Such tools could intermittently suggest information most relevant to a patients' current medical situation, reducing the responsibility placed on patients to remember information over extended periods of time. Further, these systems could utilize patient input, such as the side effects they are experiencing, to further tailor the provided information to the individual needs of the user. Adaptive systems would thus reduce information overload by increasing the relevance of information presented during treatment and transition periods, and reducing the burden placed on patients to recall important health information later in the journey.

This gap in MyJourney Compass use, and potentially strategy for encouraging more continuous use of health information, provide the primary motivation for the MyPath system, described in the next chapter.

## **6.5 Summary**

The My Journey Compass project consisted of a deployment of tablet computers preloaded with a suite of health, communication, and entertainment applications for breast cancer patients to use from diagnosis throughout treatment and into survivorship. These results of this work help to provide insight into the overarching question: What are the critical design goals and technical features for a system that supports patients' health management over time? In particular, a number of features emerged as aiding adoption of the technology and encouraging continued engagement with the devices. These features include patients' ability to customize content, integration of health and personal resources, mobility, and privacy. These features reveal opportunities for health tools to provide more comprehensive support to cancer patients, and were used to guide the design of MyPath (chapter 7).



## **CHAPTER 7**

### **MYPATH SYSTEM DESIGN**

My formative work with cancer navigators and survivors, as well as the MyJourney Compass deployment, point to a number of opportunities for mobile technologies to better support individuals dealing with long-term health issues. In particular, this work highlighted the need for support that is personalized, comprehensive, and adaptive.

I developed MyPath to address these three needs. MyPath is a mobile application that recommends trusted, online health information to users. The recommendations are personalized based on diagnosis, treatment, and gender. The recommendations automatically adapt over time as patients progress through various treatments. In addition, the application includes a questionnaire and updates content based on user responses.

The overarching goal of MyPath is to help patients find information regarding the complex patient ‘work’, that includes and extends beyond their physical health and treatment [91]. The application connects patients to trusted online health information recommended by their oncologists. Unlike many other mobile applications, MyPath does not focus on a particular behavior or health goal, such as nutrition or fitness [115]. Rather, my goal with MyPath was to provide users with a range of health information pertinent to their location in the illness trajectory, and provide specific information based on user input of their particular needs.

In this chapter I describe the design of MyPath, as well as the usability tests I ran with healthcare professionals and cancer survivors. I describe some of the important changes that emerged from this usability assessment.

## **7.1 Background**

### 7.1.1 Guidelines from formative work

The previous studies, described in chapters 4-6, led to a series of design requirements for the MyPath system. First, work with cancer navigators and oncologists revealed the importance of comprehensive care. In particular, the importance of issues such as loneliness and emotional wellbeing, were discussed in the card sorting exercise. The impact of these issues on one's ability and willingness to receive care demonstrates the need for MyPath to include content for overcoming challenges related to emotional, social, financial, and logistical issues. My work with the cancer navigators also showed the value in support systems that are personalized and flexible, adapting based on where patients are in their treatment paths. However, the personalized support offered by the cancer navigators is limited. Navigators' time constraints force them to prioritize support for newly diagnosed patients. Therefore, MyPath was designed to offer support that is personalized, adaptive, and continuous throughout the cancer trajectory.

My visual narrative study with cancer survivors helped detail the number of challenges patients experience in parallel. Many of these issues a system would not be able to automatically detect, such as struggling to talk to family and friends about one's health situation. Thus, I added the NCCN distress survey to the application to allow participants to find information regarding a range of common health and personal challenges. Using the journey framework described in chapter 5, I also added responses to the standard NCCN questionnaire.

Finally, the MyJourney Compass helped to detail important technology features that I can continued to use in the MyPath study. In particular, mobility proved important for many participants, and thus I continued to deploy MyPath on android tablet devices. I have continuously used tablets in this research, as opposed to the more common mobile phone, as the larger screen makes reading text easier. This enhanced accessibility is particularly

important for breast cancer tools, as the patient population is generally older and more likely to be coping with declining vision. Further, as the patient population is predominantly women, I have found that tablets are easy for participants to transport as many of them have purses or other bags that they take with them throughout the day.

Allowing participants to modify the device by adding their own content was important for encouraging continuous engagement, and so participants could again add content to the MyPath tablets. In addition to continuing to use the features that were successful, I developed MyPath to assess how technology may overcome a limitation in MyJourney Compass use- participants seldom used the health information after an initial burst of information seeking immediately following diagnosis. As I discussed in the previous chapter, this usage pattern is concerning when evaluated alongside other literature in health information seeking behaviors, which highlight the challenges patients' face to recall information when needed. Thus MyPath was also developed to explore if and how personalized content could encourage more continuous use of health information.

In summary, the MyPath system design and evaluations, described in the next section, build on past work by: 1) Addressing the challenges of patient work by creating strategies to provide relevant and trusted information. 2) Exploring the impact of providing personalized and adaptive recommendations on information use and trust. 3) Demonstrating how a holistic approach to patient engagement helps patients initiate new behaviors.

### 7.1.2 Recommendation systems

Though less common in healthcare, the CHI community has a long history of designing and evaluating systems that offer personalized recommendations to users. These systems are now pervasive in many aspects of life, including e-commerce, entertainment, and social media. HCI research has helped in enhancing the usability of recommendation systems, demonstrating the importance of factors such as transparency [116] and accuracy [117].

Recent literature has highlighted an opportunity for systems to use personalization to

increase a system's persuasive influence and encourage behavior change [118]. A recent example demonstrated the ability for personalized messages to encourage smoking cessation [119]. I expand on this work, providing an approach to developing personalized systems that encourage and support health management, but without limiting the focus to a single behavior change. Rather we provide comprehensive content that allows users to overcome their personal health management challenges. My work also helps provide insight into the usability of recommender systems within a health context.

## **7.2 Healthcare partnership**

Harbin Clinic were important collaborators in creating MyPath system. This partnership spanned all phases of the project, including the design and deployment of MyPath. I worked with a team of oncologists, oncology nurses, cancer navigators, and the director of operations at the clinic. The team collaboratively discussed and agreed upon providing personalized health information to cancer patients. The healthcare team determined which online health information to include, in order to ensure that only trusted health information recommended by the oncology team were used in the application.

I also worked with the director to hire an education navigator, who was hired to be an employee within the cancer clinic. This was necessary as the previous education navigator had moved out of Rome, GA. Further, the cancer navigators had gone through a significant organization restructuring which made them less available to support the MyPath deployment. In this study, the education navigator serves several roles. First, she is responsible for meeting newly diagnosed patients and enrolling them in the field deployment. As an employee of the cancer clinic, the education navigator has access to the electronic medical record and is able to see when someone is diagnosed with breast cancer within the clinic. The education navigator also provides training for each participant, reviewing the resources on the tablet and going over the MyPath features. Finally, the education navigator provides all participants with her contact information so that they may contact her with questions or



concerns about the technology or the research study. Similar to the MyJourney Compass study, the education navigator helps to reduce the potential stress placed on participants. Since the education navigator was hired as an employee of the cancer clinic, she is more accessible to patients than the other members of the research team. Further, I wished to be sensitive to patients' needs following a cancer diagnosis, as it can be a very emotional time.

The use of an education navigator allowed us to recruit participants through the cancer clinic and demonstrate to participants that their health team actively supported this application and study. This method was important for developing participants' trust in the technology and the information included within the application. As I reveal later in this chapter, participants stated that trusted the MyPath application more than many other commonly used health information resources, such as the Internet, printed materials, and family and friends. Participants indicated that the trust they felt towards the application paralleled the trust they had towards doctors and navigators. This similarity was likely due to the fact that we made evident to participants that these health professionals were actively involved in and supportive of the technology. Participants' willingness to therefore trust the included content begins to demonstrate the ability for technology to provide complementary support and information to patients when health professionals are unavailable.

### **7.3 MyPath design**

My overarching goal for MyPath is to help patients find information to support complex patient 'work', that includes and extends beyond their physical health and treatment [41]. The application connects patients to trusted online health information, recommended by our oncologist partners. Unlike many other mobile applications, MyPath does not focus on a particular behavior or health goal, such as nutrition or fitness [9]. Rather, I aim to provide users with a range of health information pertinent to their location in the illness trajectory, and provide specific information based on user input of their particular needs.

Figure 7.1 shows an overview of the MyPath system and features, which include a)

main page with resources organized into categories, b) a set of personal resource recommendations, and c) the NCCN distress survey. To use MyPath, the education navigator first setup a basic user profile for each participant with their diagnosis and treatment information. MyPath then presents a set of personalized information grouped into seven categories: a breast cancer overview, local resources, treatments, day to day matters, social support, emotional support, and health & wellbeing. To get information that is further tailored to one's specific needs in a given moment, the NCCN survey is also included in the application. After a participant completes the survey, MyPath immediately updates with information relevant to their responses. A more detailed review of the MyPath features can be found in Appendix B.

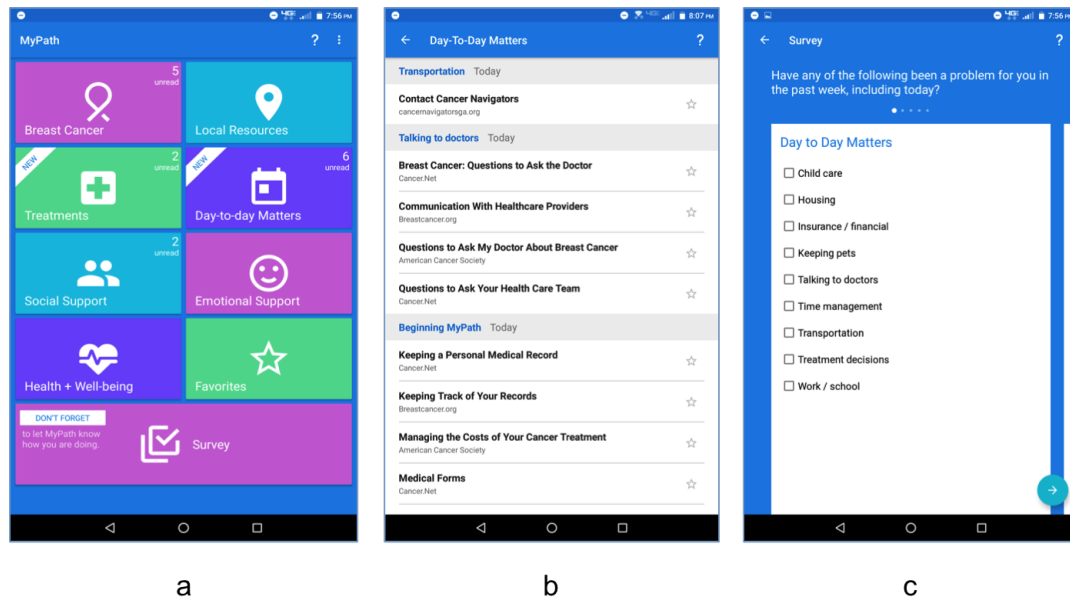


Figure 7.1: MyPath features

### 7.3.1 Content and organization

Once a user's profile is set up, they have access to a personalized set of health information. As previously mentioned, MyPath only includes health information recommended by our oncology partners. These sources include American Cancer Society, Breastcancer.org, and Cancer.net.

Typically, newly diagnosed patients at the cancer clinic will receive a binder with printed materials from these three sources. However, not all of the information is included in the binders. If more information is needed then the responsibility is placed the patients to go to these websites and find relevant information. I included all content related to breast cancer from these three websites on MyPath. This included 115 resources from American Cancer Society, 166 resources from Breastcancer.org, and 33 resources from Cancer.net. I use the term resource as a label for each unique page of information included in these websites.

### *Resource categories*

Each of the three primary information sources had a unique organization schema for the included information. Within MyPath I wanted to use a categorization that aligned with patients' mental model of health management and information needs. I found through conversations with survivors and healthcare providers that the cancer clinic utilizes the NCCN distress thermometer to understand patients' needs and challenges. The NCCN organizes common patient issues into five categories: practical problems, family problems, emotional problems, spiritual/religious concerns, and physical problems. Patients are asked to complete the questionnaire occasionally while visiting the clinic. Since patients at Harbin clinic were already using this questionnaire, I opted to utilize this categorization within the MyPath application. I did make some adjustments to the categories to better fit the MyPath content. Specifically, I removed the spiritual concerns category, as few resources included in MyPath addressed this topic. I also added a breast cancer category that included resources that provided a general overview of the disease, and therefore did not fit any of the original NCCN categories. Finally, I split resources related to physical problems into two categories: 'Treatments' and 'Health + Wellbeing'. I made this change to prevent one category from including too many resources, as this could hurt the usability of the system. The screenshot of MyPath also shows one additional category titled 'Local Resources'.

This category, and its contents, were added based on feedback from the usability study. I explain this category in more detail in the results section.

### 7.3.2 Personalization

#### *Adaptive content*

The primary goal of MyPath is to offer patients personalized health information that changes over time. MyPath includes two types of personalization: adaptive and adaptable content. Prior work has differentiated adaptive and adaptable interfaces, in which adaptive interfaces are system-driven, and adaptable interfaces are user-driven [120]. The adaptive, system-driven content in MyPath is based on a user's treatment dates, and requires no user input other than the initial setup by the education navigator. At start up, the MyPath application queries the MyPath server for updated content, caching this locally using HTML5's Application Cache.

The adaptive content focuses on helping patients prepare for treatment transitions, as these can be especially difficult moments in the illness trajectory. For example, prior to beginning chemotherapy, a patient will receive new resource recommendations that include information about preparing for chemotherapy and what to expect during treatment. Adaptive content appears one week prior to beginning treatment. This decision was made based on conversations with the cancer navigators, who believed one week gave patients enough time to mentally prepare, and was typically when patients would express concern or questions to navigators about upcoming treatments.

#### *Adaptable content*

I also wanted to allow patients to modify the system to support their needs in real time. Therefore, I included adaptable personalization in MyPath, driven by user input. Patients may complete a survey at any time that updates the MyPath content. The questionnaire in MyPath uses the NCCN distress thermometer. The NCCN distress thermometer includes

two questions. The first asks participants about their level of distress over the past week, scored from 1 to 10. I included this question in MyPath in order to evaluate the severity of issues patient encountered. If patients indicated a distress level greater or equal to 4, the application recommended that they contact one of their healthcare professionals, and included contact information to the cancer clinic and cancer navigators.

The second question in the survey asks patients to select which issues the patient encountered over the past week. The survey includes 38 possible responses, including common side effects, as well as practical, family and emotional problems. Example responses include fatigue, nausea, pain, sleep, insurance, transportation, depression, fear, and dealing with children. In addition to the issues included in the distress thermometer, we added 22 other possible patient challenges, which emerged from the visual narrative study with cancer survivors. Examples of added survey options include *talking to doctors* and *infections*. Table 7.3.2 shows all of the possible survey responses. Responses that were added to the original NCCN questionnaire, based on my previous studies, are bold.

### 7.3.3 Favorites

While the adaptive and adaptable content both help to add personalized content, no health information is ever removed from the application. I therefore included the favorites feature to help users manage information that they wish to return to. Patients may select the star next to a resource to favorite it, and view it in both the original category as well as the favorites list.

### 7.3.4 Technical implementation

Jeremy Johnson, a research scientist within Georgia Tech's Interactive Media Technology Center (IMTC), was the primary developer of the MyPath application. MyPath is implemented as a native Android application supporting Android 5.0 and later. While designed for 7-inch tablets, the app's responsive design can also support a variety of screen sizes. The

Table 7.1: MyPath survey options

<u>Day to Day Matters</u> Child care Housing Insurance/financial <b>Keeping pets</b> <b>Talking to doctors</b> <b>Time management</b> Transportation Treatment decisions Work/school	<u>Social Support</u> Ability to have children Dealing with children Dealing with partner Family health issues <b>Social support</b> <b>Talking to others</b>	<u>Emotional Support</u> Depression Fears, nervousness, worry Loss of interest in usual activities Sadness
<u>Treatments</u> <b>Anemia</b> <b>Bleeding/ blood count</b> <b>Bone health</b> Breathing Changes in urination Constipation <b>Dehydration</b> Diarrhea Fatigue Feeling swollen Fevers Indigestion <b>Infections</b> <b>Leg cramps</b> <b>Lymphedema</b> Mouth sores or dryness <b>Nail changes</b> Nausea Nose dry/ congested Pain Skin dry/ itchy <b>Sweating</b> Tingling in hands/ feet	<u>Health</u> Appearance (hair, skin, nails) <b>Balance/ falls</b> Bathing/ dressing <b>Cancer recurrence</b> <b>Complementary medicine</b> Eating/ appetite/ nutrition <b>Exercise</b> Getting around <b>Getting vaccinations</b> Memory/ concentration <b>Menopause</b> <b>Reconstruction</b> Sex Sleep Substance abuse <b>Weight</b>	

application was developed to support both cached, offline accessible and live web content displayed in an embedded web view. Some resources, such as online discussion boards and embedded hyperlinks, required an Internet connection. However, the majority of resources could be accessed offline. To allow for offline access, we created simplified HTML representations of the web pages, allowing for both caching the content on the mobile device as well as providing a styling and appearance consistent with the original source.

The MyPath application was deployed on Verizon Ellipsis tablets. In addition to the MyPath application, a number of other applications were included on the tablet for the field deployment. These applications included patients' personal email, a calendar with each individual's upcoming treatment dates, and the cancer clinic's patient portal. These applications were included to further personalize the tablet system. We also added several applications designed for general health management, including MyFitness Pal, Paced Breathing, and Nutrition Facts. I included these other applications on the device in order to allow the tablets to not only provide health information, but to be a useful health management aid more broadly.

#### 7.3.5 Implementing personalized content

The primary MyPath feature is the personalized resource recommendations that patients continuously receive throughout the cancer trajectory. These updates are driven both by treatment transitions and MyPath survey responses. To develop the personalization, every resource was tagged with the information shown in table 7.3.5. This metadata includes tags that allow a resource to be associated with events in the patient's treatment timeline (e.g. after surgery, or before radiation treatment) and specific survey responses (e.g. difficulty sleeping).

While the research team created the metadata tags, our healthcare partners validated that resources were appropriately characterized. I worked primarily with the director of operations to review our resource recommendations to ensure they were appropriate. The

director of operations served as one of the primary nurse practitioners for the cancer clinic prior to taking over the director role, and was therefore well qualified to provide feedback on the applications' content.

### *Treatment Transition Updates*

For each MyPath user, a short profile is completed that includes their treatment dates. These dates are used to signal a transitional event, and thus generates recommendations based on patients' treatment paths. Updates based on transitional events are stored using temporal tags, which are included in each resource's metadata. The majority of resources appear one week before a new treatment, to help a patient learn what to expect and prepare for this change. For example, if a patient's first treatment is chemotherapy, which begins on October 7, 2017, then the system will identify the start date minus seven days, or October 1, 2017, as a transitional event, and the user will see all resources tagged with the temporal tag 'Before chemotherapy' on MyPath on October 1, 2017.

Similarly, several resources, many of which include content about managing side effects, are tagged to appear one week after a patient begins a new treatment. So if a patient begins chemotherapy on October 7, 2017, resources that include the temporal tag 'During chemotherapy' will appear on October 14, 2017.

Figure 7.2 shows an example of the tagged metadata. The example shows that the informational page "Hormonal Therapy: What to Expect" is recommended to patients in the Treatments category of MyPath one week prior to beginning hormone therapy, as it includes that temporal tag Before Hormone Therapy.

### *Questionnaire Updates*

New recommendations are also presented when the user completes the MyPath survey. As previously mentioned, this survey is always available to patients on the MyPath application, and asks patients to indicate which problems they have experienced over the past week. In



order for the system to immediately recommend resources that are relevant to a patient's survey response, I have included survey response tags in the resources' metadata. These tags indicate if a resource's content pertains to a particular response in the survey. Thus, when a patient selects a particular response in the survey, such as 'Nausea', all resources that have content related to that subject will immediately appear in the application when the survey response is submitted. Each survey response is tagged to at least one informational resource (min = 1, max = 22, median = 3). 'Insurance/finance' was the survey response that corresponded to the most resources (n=22).

Several survey responses corresponded to only one resource, including 'child care', 'keeping pets', 'dealing with partner', 'changes in urination', 'constipation', 'feeling swollen', 'fevers', 'leg cramps', 'dehydration', 'sweating', 'blood count', 'bathing/dressing', 'getting around', 'sleep', and 'balance'. The absence of information on these main websites about common health issues that patients face points to a need for information that more closely aligns to patients' daily concerns and an opportunity for future tools to bridge these info.

```
{
  "uid": 199,
  "title": "Hormonal Therapy: What to Expect",
  "contentHref": "content/199/index.html",
  "originalHref": "http://www.breastcancer.org/treatment/hormonal/
expect",
  "onlineOnly": false,
  "category": "TREATMENTS",
  "temporalTags": [
    "BEFORE_HORMONE_THERAPY"
  ]
}
```

Figure 7.2: Metadata Example

### 7.3.6 Capturing tablet use

MyPath application usage was tracked with Google Analytics. I captured all events within MyPath, including movement between screens, survey submissions, and resources viewed.

Table 7.2: Resource metadata used to create MyPath personalization

Tag	Description	Options	Example
Category	The MyPath section in which the resource would appear	Breast cancer overview Local Treatments Day to day matters Social support Emotional support Health and wellbeing	"Talking with Friends and Relatives About Your Cancer" falls under the Social Support category. category.
Temporal tags	When in a patient's treatment path the resource would appear	Initial setup Before lumpectomy Before mastectomy Before surgery (all) After lumpectomy After mastectomy After surgery (all) Before first treatment (any) Before chemotherapy Before radiation Before hormonal therapy During chemotherapy (one week after start) During radiation (one week after start) During hormone therapy (one week after start)	"Chemotherapy: What to Expect" is tagged to appear Before Chemotherapy. "Managing Side Effects of Radiation" is tagged to appear During Radiation (which will show up one week following a patients' first radiation appointment.
Survey Response tags	When a patient completes the MyPath survey, resources associated with their response(s) immediately appear. These tags connect resources with the associated survey responses.	Any survey response. For a full list, See 7.3.2	"Questions to Ask My Doctor About Breast Cancer" is tagged with the survey response "Talking to Doctors", so when a patient selects this response in the survey, this resource will be recommended.

Data on general tablet use was collected using the AWARE Framework. Through the framework I captured all applications used, date and time of use, and duration of use. Like the MyJourney Compass study, I did not collect any content within applications, except for MyPath, in order to respect participant's privacy.

Data collection of tablet use is currently ongoing and I therefore do not fully report on this data within the thesis. Rather, in chapter eight I focus on the results and contributions of the qualitative study examining how patients integrate this technology into their daily lives.

## **7.4 Usability evaluation**

### 7.4.1 Methods

Personalized and adaptive content adds a complexity to an application's interface. I therefore wanted to ensure that such complexities did not interfere with the usability of the system, particularly due to the range of ages and technical literacy in the participant population. However, testing the usability of MyPath presented an interesting challenge, as the content changes over time.

In order to assess the usability of MyPath's dynamic content, I created three scenarios to include in the usability assessments. The scenarios each involve a common moment in time in the cancer journey, allowing participants to view content changes as they progress through each scenario. Prior to each scenario, I updated a demo user profile so that participants could experience how content would change over time.

The first scenario focuses on the cancer diagnosis. Before viewing the MyPath application, participants were asked to reflect on either the challenge they encountered immediately following a cancer diagnosis, or common challenges patients face during this time. I began with this reflection to help us understand what each participant would consider necessary or useful health information. After this brief discussion, participants were given MyPath with the content one would see upon diagnosis. I asked participants to find one

resource that they believed would be helpful to a newly diagnosed patient, considering the challenges they just shared with us. To accomplish this task the participants needed to first select a category and then open any informational resource. Once completed, participants were asked to briefly read the information and verify that they would consider the included information as useful during diagnosis. Participants were then asked to repeat this scenario two more times, allowing them to find and review resources in other categories.

The second scenario was similar to scenario one, except focused on the beginning of a new treatment, such as chemotherapy or radiation. Participants once again reflected on common challenges and information needs just prior to beginning a new treatment. After this reflection, I again presented participants with the MyPath application and asked them to find useful information about the challenges they articulated. Participants were not given forewarning that MyPath updated to include content relevant to beginning treatment. I therefore used scenario 2 to assess if content changes were noticeable and if content changes affected the ability for users to find useful information.

In the final scenario, I asked participants to discuss common challenges and information needs that arise in the middle of treatment. I then asked participants to complete the questionnaire in MyPath, which asks about ongoing challenges, and find information that could help with the challenges selected in the questionnaire.

Throughout the usability study, I asked participants to think aloud. All studies were audio recorded and transcribed for analysis. I also asked participants to complete pre- and post- study surveys. The pre-study survey collected demographics and asked participants to score their technology comfort on a scale from 1 to 5. In the post-study survey, participants were asked to share what they liked and disliked about the application.

#### 7.4.2 Participants

In total, 7 health professionals and 4 cancer survivors participated in the usability assessments. I included healthcare professionals who work directly with cancer patients, due to

their ability to reflect on a variety of patient experiences. These professionals included oncology nurses and cancer navigators associated with our partnering cancer clinic. On average the healthcare professionals had 16 years of experience working with breast cancer patients. I also ran usability studies with cancer survivors who had recently completed treatment, as I believed they would best be able to reflect on their own health information needs while also considering how these needs changed over time. All of the participants were women. Participants' ages ranged from 23 to 67. Participants' technology comfort ranged from 1 to 5, with an average score of 3.8. When sharing quotes from the usability studies below, I refer to the healthcare professionals as H1-H7 and cancer survivors as S1-S4.

#### 7.4.3 Usability feedback

One of my primary concerns before deploying MyPath was that the adaptability of the applications' content would interfere with the usability of the system. Work studying adaptive interfaces has indicated that adaptive systems could be slower and less preferable than static or adaptable interfaces [120]. I had two overarching goals with the usability assessments. I first wanted to ensure that participants would be able to navigate the dynamic content to find useful information. Secondly, I wanted to ensure that the content included matched participants' expectation and information needs. In the remainder of this section I discuss the results of the usability tests pertaining to these two goals.

##### *Navigating dynamic content*

During the usability testing of MyPath, I saw no general navigation issues. All participants were able to move between categories, select and read resources, and scrolled to view longer lists.

Participant feedback regarding system navigation was overall positive, particularly in the post-test survey. Although the post-usability questionnaire used open-ended questions

that did not specifically ask about navigation, seven participants commented that the application was *easy to use* or *easy to navigate*.

I wanted to ensure that participants recognized that content was changing over time, as they progressed through each scenario. Several participants made comments during the think aloud protocol indicating that they recognized content changes. Comments about these changes were generally positive. For example, one healthcare professional commented that she agreed with the process of providing a subset of resources at first and then adding more over time:

*I think its important to have just a few resources (at first) and then you give them a little bit more, so I think that's good - H1*

One of the cancer survivors also commented that the updated content felt like it was being curated specifically for her:

*It seems like those things are sent directly / specifically to me by the creators - S2*

These comments regarding the adaptive content helped reveal that participants did recognize the changes to the application that occurred. No participants made negative comments regarding the updated content or appeared flustered by the unexpected changes. In fact, as the quotes above shows, many participants saw the content updates as a positive and helpful feature.

I also compared the completion times for scenarios 1 and 2 to determine if the content changes affected participants' time or ability to find useful resources. I calculated completion time as the time between being asked to find a resource and opening a resource page. As shown in figure 7.3, participants completed scenario 2 faster, despite content updates. This result suggests that adding content over time does not impede on users' ability to use the application to find health information.

I did encounter a navigation issue during the third scenario. Several participants struggled to find the information relevant to the survey selections they submitted. Participants shared similar frustrations after completing the survey and being uncertain where to go to

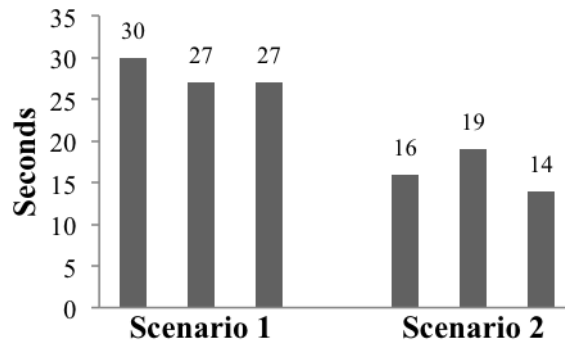


Figure 7.3: Completion times for the first and second scenarios in the usability study

find the new content. As one participant stated:

*How do you get to the new recommendations? I don't know! - S1*

Interestingly, this confusion occasionally led to fortuitous results. Many participants selected a different category than the survey responses they has entered. However, they often found resources in those categories that caught their interest and would read through, despite not directly addressing the issues they initially discussed in the scenario.

#### *Content Quality*

My second goal with these initial MyPath usability assessments was to ensure that participants were able to find useful health information based on their own prior experiences. Generally, participants' think aloud feedback more focused on the content within the application than on system features. Participant feedback on the included resources was overwhelmingly positive. All eleven participants commented on the importance of the included information, either generally or about particular resources that caught their attention. Several participants commented that the resources were useful for setting expectations. For example, one participant commented on how the resources would have helped alleviate anxiety about what to expect during treatment, while another participant specifically identified information about side effects as being useful for setting expectations.

*I think if I could have been given expectations it would have relieved some anxiety - S3*

*Side effects will be very informative. Of course it may not apply to you, but very informative. You would know what to expect even though you may not have them - S1*

An important result was that no participants were unable to find information that matched the issues they described within scenarios 1 and 2. As previously mentioned, some participants did not complete scenario 3 due to navigation difficulties.

One of the most common criticisms I received during the usability sessions was the lack of information pertaining to the local resources available to patients. Participants recommended including more information about cancer navigators, local support groups, and programs developed in the area for cancer patients' children.

Several participants also commented on the order of the resources in each category. Three participants walked us through how they would reorder the resources in one or more categories. Interestingly, all participants who suggested reordering the content said their recommendations were based on which resources they felt were most useful to patients, with the most important resources at the top. However, I found that none of the recommendations closely matched each other. The variation in these recommendations demonstrates how differently individuals value various health information. The difference in participants' information priorities is further supported by the variability in the resource selections in each scenario. Figure 7.4 shows the breakdown of category selection in each scenario.

These findings show how participants' information needs and priorities can be drastically diverse. I therefore ordered the resources in alphabetical order. However, these responses indicate an interesting opportunity for future work to look at ways to alter the ordering of resources at the individual level.

#### 7.4.4 Design changes

Overall the usability assessments helped reveal a couple opportunities to enhance the My-Path system. I found no evidence through these assessments that the use of adaptive or adaptable content interfered with the overall usability of the application.



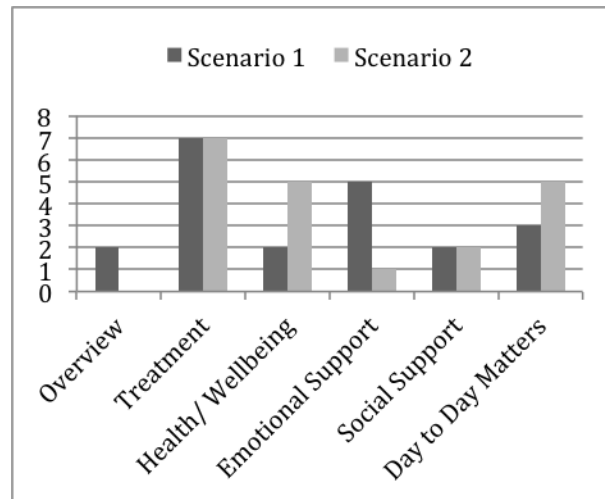


Figure 7.4: A breakdown of the categories selected by participants during the usability study scenarios.

The most evident changes included the addition of local resources, and additional application navigation support to help participants find information related to their survey responses. In order to better support navigation to new content after completing a survey I added three interface features. First, I added a message that appears after completing the survey that provides a review of submitted responses. I also added shading, so that the categories with new resources based on survey responses are highlighted. Finally, I added some basic animation to the "new" label that appears on relevant categories when recommendations are added based on a survey submission, making it more noticeable.

I also added a "Local Resources" category after the usability assessments. I collected resources to include in this section through the usability feedback, and follow up meetings with cancer navigators, employees at the cancer clinic, and a nurse at the neighboring hospital. The final Local Resources category includes nine resources from the Rome cancer navigators, Harbin, and the Redmond hospital.

## 7.5 Summary

Few tools today have explored how technology can connect patients to more comprehensive sets of health information, how to organize this information to keep it from being

overwhelming, or the use of personalization as a strategy to support health information seeking and illness management. Through MyPath, I connect patients to health information tailored to where they are in the cancer trajectory and the personal health management challenges they encounter.

## **CHAPTER 8**

### **MYPATH FIELD STUDY**

The goal of the MyPath study is to assess how technology can help alleviate the burden of health information seeking and reduce barriers to effective health management. MyPath is currently being deployed to breast cancer patients receiving treatment at Harbin Clinic. To evaluate the effects of personalized and adaptive tools on patients' health management and quality of life, I ran a qualitative study of participants' use of MyPath throughout treatment. The results show that patients' use of the application led to direct changes in their health management behaviors, demonstrating the value of personalized and adaptive health interventions.

A number of contributions from this work have emerged, including:

1. I validate the usability of MyPath's personalized and dynamic content with breast cancer patients undergoing treatment. My results indicate that MyPath provides patients with content that is both easy to access and trusted, filling a gap in existing health information sources.
2. I describe how providing patients with personalized health content influences health management behaviors. I found that participants developed more consistent health information seeking routines than documented in other literature. Further, use of the application catalyzed health management tasks and supported emotional wellbeing.
3. I use the Health Belief Model (HBM, [121]) to reflect on why personalized information systems encourage behavior change; motivating the need for customized content to be more widely adopted by personal health management tools.

## 8.1 Methods

### *Research questions*

I developed the MyPath field study to identify opportunities and barriers for using personalized health information systems to reduce health information seeking challenges. Several questions guide this study. First, would patients trust a mobile application that connected them to online health content? Previous research has demonstrated that there is a large spread in the amount of trust individuals place in online information [46]. Second, would use of dynamic content impede on the usability of the application? I was concerned about the system's usability as dynamic content can have consequences on participants' ability to access information [120]. Lastly, would use of the application influence health management behaviors? Prior work has demonstrated that more informed patients were more actively engaged in their health care [122].

### *Participants*

The education navigator recruited patients during their education day, when patients meet with the oncology team to learn about their specific treatment path. On this day, participants received their tablet and a brief training about how to use the tablet and MyPath application.

In August 2017, I interviewed all participants who had enrolled in the MyPath field study. This included eight participants. Five of the participants received radiation therapy during the study and three received chemotherapy and all were diagnosed with stage I or II breast cancer. Participants' ages ranged from 49 to 74 (mean = 66). We asked participants at their first meeting with the education navigator to score their technology comfort from 1 to 5 (1=very uncomfortable, 5=very comfortable). Participants' responses ranged from 3 to 4 (mean = 3.6).

### *Data collection and analysis*

I interviewed all participants about their cancer care experiences and use of the tablets. All interviews included one participant and one researcher, except for one participant who also brought her primary caregiver (her daughter) to the interview, as they often used the tablet together. At the time of the interviews, participants were either in treatment or had recently completed treatment. On average, participants had the tablets for 10 weeks, with a maximum time of 18 weeks and minimum time of 4 weeks.

I audio recorded and transcribed all interviews. To analyze the data, the research team used an iterative inductive analysis [123]. As the primary researcher, I independently coded the transcripts. The research team then reviewed the transcript segments and associated codes, and collaboratively refined the codes to identify emergent themes around tablet use.

## **8.2 Results**

### 8.2.1 General tablet use

Participants were able to add their own content to the tablets and use the devices however they wished. The MyJourney Compass study showed that this openness and flexibility encourage use. While use of the broader tablet device was not the primary focus for this study, I found that participants used the tablets in similar ways discussed in the MyJourney Compass deployment. Many participants used the calendar to track appointments and the patient portal to look up test results. Seven out of eight of the participants also added their own content, including Bible applications, games, books and movies. Most participants used the tablets for both personal and health related tasks, although three participants said that they used the tablets solely as a health tool.

### 8.2.2 General MyPath use

While the remainder of this chapter focuses on the results of the qualitative investigation of MyPath use, here I present a short overview of use based on tablet usage logs. Participants used the MyPath application for a total of 114 unique sessions, which lasted an average of 7 minutes (range = 1 - 60 minutes). During these sessions, participants collectively completed 92 surveys. Surveys on average took 25 seconds to complete. Interestingly, participants' use of MyPath included resources from all MyPath categories. Below is a breakdown of which categories were viewed during MyPath use.

Treatment: 30% of sessions

Day to Day: 23%

Health and Wellbeing: 20%

Local: 15%

Overview: 14% of sessions

Emotional Support: 13%

Social Support: 7%

### 8.2.3 Usability and trust of dynamic recommendations

Connecting individuals to personalized and dynamic health content can have unforeseen consequences on the usability and effectiveness of an application. While I ran usability studies with health providers and cancer survivors, I was also interested in whether patients would be able to easily access information as new resources were recommended. Recall that the tablet contained 314 curated pages of information and that patients are frequently overwhelmed with this information presented in printed and static formats [29]. I was also concerned about whether participants would trust the content within a new application. While online health seeking is becoming more common, past research indicated a general distrust of online information, particularly by older adults who were not confident in their ability to find accurate information online [54].

To gather usability feedback, I asked participants in the interview to describe the MyPath features, and share any challenges they encountered while using the application. Participant interviews indicated that patients understood the technology, features, and dynamic content. All participants commented that they found the application easy to use and could accurately describe the tablet features, demonstrating their understanding of the dynamic content:

*I think it's amazing that you can sit there and just fill in the survey and it will give you different suggestions it's very helpful. P1*

*I answer the questions and it pops up with a bunch of new information. P3*

I had one participant who infrequently used technology. She owned a mobile phone that she used only for taking pictures. She shared that after a month of completing surveys with her daughter's help, she began completing them herself, and found the application easy to navigate:

*I thought it was easy to use, I liked that the articles were right there when you finished. Really easy to navigate. P5*

These discussions demonstrate that dynamic content did not hurt the usability of the system, even for participant with little experience using technology. However, as noted above, participants indicated a general comfort with technology (mean=3.6/5). More research is needed to determine if dynamic content serves as a barrier to use for individuals with lower technology comfort.

To examine participants' trust of the MyPath application, I asked participants to complete a short questionnaire after the interviews. The survey listed six sources of health information: doctors, cancer navigators, friends and family, printed materials, MyPath, and the Internet. In the survey, participants indicated which of these sources they used since their diagnosis. I then asked participants to score how easy it was to access each information source and how much they trusted the information sources on a Likert scale from -2 to 2. Figure 8.1 shows the results of the questionnaire.

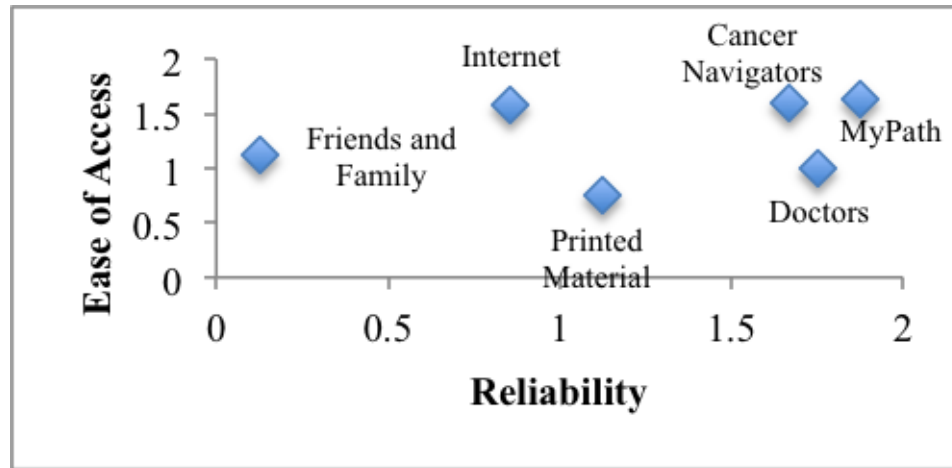


Figure 8.1: Participants' scores indicating the ease of access and trust of health information sources.

The results shown in figure 8.1 reveal an important gap in existing health information resources. Looking at the resources that are widely available, including friends and family, Internet, printed material, and doctors, we see that none of these sources are considered by participants to be both very reliable and very easy to access. Cancer navigators help to fill this gap, but are not available to all participants, and are not able to provide long-term, continuous support. Thus, the most significant implication of this comparison is that MyPath complements navigation practices by being both accessible and reliable. Since cancer navigation groups are not widely available, applications such as MyPath that provide tailored, trusted health information may help fill an important gap in existing health information sources.

Many aspects of the MyPath study likely contributed to participants' trust of this novel technology. Primarily, participants received the technology through the cancer center, demonstrating that their healthcare team supported use of the application, and all incorporated content. In addition, each resource recommended on the application includes a heading stating which website was the original source of the information (American Cancer Society, Cancer.net, or Breastcancer.org). This small detail helped to improve the transparency of the system by allowing participants to know that the content was retrieved from



a reliable source.

A examination of figure 8.1 also provides some interesting insights into the different expectations patients hold towards various health information resources. For example, the Internet and cancer navigators were scored as being comparably easy to access. This equivalence is surprising as cancer navigators are only available during typical business hours, and during this time are working with many patients, while the Internet is always available to participants (the MyPath tablets included a one year data plan). The fact that these participants believed that both of these resources were easy to access suggests that the standards participants place on each health resource are variable. For instance, while cancer navigators are not available 24 hours a day, they are available during the work day, when participants are typically at the cancer clinic, and allow for walk-in meetings. Thus, while cancer navigators are available for fewer hours, particularly when compared to the Internet, each of these resources met patients' expectations regarding access. Thus, the results in figure 8.1 demonstrate that patients do not hold the same expectations towards all information resources. Understanding these differences presents an opportunity for future work that could further help to determine strategies for improving access and trust in health information sources.

#### 8.2.4 Influence on health management

In addition to examining whether patients going through cancer treatment would find MyPath usable, I was interested in how use of the application would influence health management behaviors. The interviews revealed that participants routinely used the MyPath application, and that the information served as a catalyst for personal health management tasks, and also helped to support participants' emotional wellbeing.

##### *1. Routine Development*

One surprising result was the consistency in which participants engaged with the MyPath application. Two participants said they used the application several times a week,

and all eight participants created consistent routines for completing the survey and looking through the recommended content. Every participant stated that they had designated a specific day of the week to complete the survey, as illustrated in these comments:

*I always go on Monday to do the survey. P2*

*I was doing the survey on Wednesday so I probably read it on Wednesday. P3*

*I mainly did it the first of the week to get it taken care of, like on Monday or Tuesday First thing in the morning when I get up, with my coffee. P4*

To help them maintain these routines, participants created various reminders to ensure they completed the survey. Some participants would use calendar reminders, while others would use the location of the tablet as a visual cue:

*I just put it in my calendar to do each Friday, so I just do it each Friday and then it comes back with whatever I said I'm having issues with. P6*

*It stays on my coffee table, where I sit and watch TV. If I think of something to look up I'll look it up. P4*

Though participants commented that the survey took only a minute or two to complete, they typically estimated that they spent 20-30 minutes reviewing content immediately after filling out the survey. Participants also commented that they believed without MyPath they would not have looked up health information as often:

*[Without the tablet] I wouldn't have gone out to research stuff. I've read more about it because of the tablet, definitely. P6*

*I haven't done a whole lot of [online health info seeking]. There's so much information that I'm getting, along with the links that are in the articles, that I haven't had to feel the need to go to much out on the web and look P7*

To verify if participants' descriptions of these routine behaviors aligned with actual system use, I looked at the MyPath survey completion rates. I compared the number of weeks participants had the tablets to the number of surveys completed by each participant and found that participants' average weekly survey completion rate was 81.7%.

Developing routine health information seeking is an important behavior for cancer patients. Prior work has shown that patient health information needs are continuous and evolving [124, 34]. However, health information seeking typically declines over time, with more aggressive information seeking done early in the cancer journey, immediately following diagnosis [27], which can lead to patients forgetting the information they previously read [122]. Encouraging consistent health information seeking for ongoing issues may help to reduce the common issue of patients feeling uninformed about their illness.

## *2. Stimulating Action*

In addition to reading health information regularly, six participants described specific ways that the information they read led to immediate actions, including managing side effects, integrating new healthy behaviors, talking to health professionals, and talking to others about the disease.

Four participants talked about how they used tips from the readings to manage side effects. Typically the tips that were used were direct recommendations for home remedies, such as mouthwashes that help with mouth sores or lotions for dry skin. For example, one participant described getting new lotion to help with the effects of radiation:

*I have very sensitive skin anyways, and I was getting very dry skin. I had like a sunburn effect. It was telling you different lotions and things you could use. P1*

Another participant used the information to figure out what to eat while going through chemotherapy:

*I've mainly used the nutrition, because I needed to know what not to eat, what not to drink. Don't use creamer in your coffee, drink the water. P4*

Three participants shared that the information they read on MyPath encouraged them to talk with their health providers. This behavior occasionally was due to having questions that arose while reading the information. One participant even said she chose to complete the surveys the day before her doctor appointments so that she could bring up the information if needed:

*It made sense for me [to fill out the survey the day before treatment], because that way if I had questions I was seeing him the next day P2*

This same participant did share a specific time in which this pattern was useful. The participant was reading material about different stages of breast cancer and got confused about her own diagnosis. She then talked to the doctor the next day about the confusion and had him write down her specific diagnosis details.

Participants also used the materials to figure out which side effects they should discuss with their doctors. For example, one participant had read about other patients' experiences on the breastcancer.org forums, a resource recommended on MyPath, and based on their stories she decided she should tell her doctors about the side effects she was experiencing. This discussion ended up leading to important conversations with one of the chemotherapy nurses:

*It got me thinking maybe I should tell them more about the little side effects because you never know what could be really important. We started talking about the neuropathy in my fingers and she told me don't let it go too far. Right now we are just going to watch it because it just started. But she told me not to let it go too far because if it does it may not be reversible and they have things they can prescribe to help with it. So that was important to tell them. P7*

In addition to talking to doctors, three participants said that they looked up information about how to talk about the illness with others, such as friends and family members. As one participant described, she was struggling with friends and family talking too often about her cancer, and the information she received helped her communicate with them better:

*It's helped me to figure out how to communicate and just say, this shouldn't be our only conversation, this is just a part of my life. P6*

These various activities demonstrate that participants not only read the content on MyPath, but also used the information in their health management. Tasks such as managing side effects, communicating with providers, and maintaining a social support system are

important health management behaviors, and have all been shown to improve patients' overall quality of life [100, 88].

### *3. Managing Emotional Wellbeing*

Six participants shared that they used the information on MyPath to manage their emotional wellbeing during treatment and reduce fear. One way in which the information helped accomplish this effect was by helping them set expectations about their particular treatment paths:

*I try to know a little about the side effects for what I'm going through, which so far have been minimal, but then you know what to expect P6*

Managing expectations is an important aspect of patient work. Research has shown that by developing realistic expectations through health information, patients can improve their confidence in their own ability to handle issues they encounter as a result of their illness [3].

Participants also commented that getting information about the side effects they were experiencing helped them to determine if the side effects were typical for cancer patients:

*I was suddenly getting pimples, and it was answering questions about how radiation affects those things. P1*

*I can look at side effects and figure out what's normal, what's not normal. P7*

Managing the emotional effects of a cancer diagnosis can be a challenging process for patients [125]. Participants were able to describe two ways in which having information about their specific treatments and side effects helped to reduce fear and anxiety: by setting expectations for the future, and helping patients determine if their existing side effects were normal.

#### 8.2.5 Ideas for improved personalization

The previous results demonstrate the benefits of the MyPath system. Interestingly, I also found that providing some personalized content to participants helped to stimulate conver-

sation and ideas about how future tools could be better designed to fit their individual needs. For example, participants commented that they would like to see different survey questions based on treatment, since participants in radiation felt that many survey responses were not relevant for them:

*Divide it up for specific treatments. The survey could be geared towards the diagnosis, the surgery, and you could have it so that the survey changed. And then it could be geared toward if you're having chemotherapy or radiation. P2*

While I relied on a consistent survey for this research probe, the clear opportunity for improvement provided a simple way that participants could imagine more tailored support. This initial idea then led to more in-depth discussions on opportunities for enhanced personalization. The most common idea that arose in conversations was personalized information for managing comorbidities. Six participants described other health issues that they were managing alongside cancer. These conditions included underactive thyroid, chronic kidney disease, and fibromyalgia. Several participants expressed the need for information to help them understand how to manage these conditions in parallel, particularly when recommended health behaviors for cancer went against health behaviors for other health issues:

*[The oncologist] was saying drink this much water a day, but the kidney doctor was saying no, do not drink more than 50 ounces because your kidneys just can't handle that. P5*

Developing systems that can help people manage multiple illnesses can have important benefits for a large population. Currently, about 1 in 3 adults with breast cancer in the United States are living with multiple chronic illnesses [126].

Typically, these opportunities for enhanced personalization did not derail use of the MyPath application. Rather, these discussions demonstrated how participants' expectations of the technology was evolving, and use of the system allowed them to discover new ways in which personalization features could support their personal needs. Similar patterns of

discovery and expectation shifts have been documented in research with new mobile phone users [127].

However, when MyPath's content did not support the primary health focus of the participant, as was the case with the participant with chronic kidney disease, use of the application declined. In the next section, I describe the factors that limited participants' engagement with the MyPath system.

#### 8.2.6 Participants with low use

While participants shared many ways in which the MyPath application was useful in their health management, not all participants considered the application valuable. Three participants commented that while they filled out the surveys, they had not found the information useful and read few of the suggested resources. In my conversations with these three participants, I found that they all provided similar feedback into why they were not using MyPath.

First, all participants made comments about having low illness severity, indicating that they experienced few side effects, and possessed the tools to cope with the illness:

*I had no ill effects from the radiation. No radiation burns. I had one little tiny pimple or blister, it was really nothing. No fatigue, I feel fine. P3*

*My friend said she had really bad side effects, I said no I didn't have any. P5*

*I'm fortunate that I'm financially comfortable and have excellent insurance that pays for everything and I have friends and neighbors who have made themselves available. P8*

Second, all three participants shared personal issues and priorities that overshadowed the cancer diagnosis:

*My husband just died. P3*

*What we don't know, and need to know, is more about the kidney disease. P5*

*I really haven't found any practical application for it. Probably because the problems that I've had were not things that could be addressed with that. I was going through my*

*mother dying. P8*

Similar to having more pressing health issues, personal life events could take priority over the cancer diagnosis. Thus, these participants were less focused on managing the disease and more concerned about events external to cancer, leaving a gap between their personal goals and the MyPath content.

Finally, one participant made several comments about not wanting to look up information altogether.

*I find it easier to not talk about breast cancer I found that when I had questions about things I tried to look them up. I didn't find it comforting. I found it more disturbing because it gave me more questions to ask and more information to put in my brain. P3*

While only one participant emphasized this disinterest in health information seeking, other literature has shown that actively avoiding health-related information is a common behavior [128]. Studies using the HBM to understand health behaviors have identified fear as a primary reason people actively avoid information, and a significant barrier preventing healthy behaviors [129].

### **8.3 Discussion: Why does MyPath influence health behaviors?**

There is an important, yet less explored opportunity to use personalization to facilitate access to trusted online health information. By improving access to health information, technology can have a significant impact on individuals' psychosocial wellbeing and health outcomes [3]. To support this goal, more information is needed about how patients will respond to novel technologies that provide tailored information recommendations. I developed the MyPath study to assess how cancer patients would use an application that recommended personalized and adaptable content in order to reduce common barriers in health information seeking. A key result from this work is that providing personalized, adaptable content encourages participants to develop routines for using the application. Compared to studies, including the MyJourney Compass deployment, that have looked at patients' use of



static health information sources [27], MyPath participants engaged with health information more frequently and consistently. This frequent engagement with the content helped participants to support their emotional wellbeing and motivated health behaviors, such as communicating with one's health care providers and support network.

I also found that the MyPath application allowed participants to acquire information that was both trusted and easy to access. Few health information sources commonly used by patients succeed at this combination. While cancer navigators help to fill this gap in my participants' community, such organizations are not always available and navigators face significant time constraints, limiting the time they can spend with each individual patient. Cancer navigators therefore tend to focus their time on newly diagnosed patients. Supporting patients during treatment and survivorship meets an important need.

While these results highlight the benefits of personalized health information systems, I did also identify important limitations in MyPath's effectiveness. The technology was considered less useful for individuals who had few side effects or were dealing with more significant concerns, such as other illnesses. In the remainder of this section I discuss two questions to guide the development of future tools: Why did use of MyPath influence health behaviors and what implications do these findings offer for future research and health systems?

### 8.3.1 Theory-driven reflection of MyPath use and disuse

To better understand why engagement with technologies encourages various health management behaviors, I turn to the Health Belief Model (HBM), a theory commonly used in understanding health behaviors [130, 131]. The HBM was developed in social psychology to predict illness prevention behaviors, but has more recently been used to develop systems that support illness management [132]. The theory states that the probability of a person employing a behavior depends on their beliefs, and lists six constructs that influence behavior: perceived susceptibility, perceived severity, perceived benefits, perceived barriers,

cues to action, and self-efficacy. The theory further states that modifying factors influence one's beliefs. My goal with MyPath was to encourage health management behaviors by improving patients' *knowledge* of their disease and one of the modifying factors in the HBM. According to the theory, influencing one of these modifying factors can subsequently affect personal beliefs and HBM constructs.

I found that participants talked about three HBM constructs: perceived barriers, perceived severity, and cues to action. First, due to MyPath's curated trusted health information, participants shared that the information reduced current health information seeking barriers by being both easy to access and trusted. Participants also shared that MyPath motivated them to look up health information more regularly than they would without the tablet system. Second, by providing information about one's specific diagnosis and treatment, participants were able to set realistic expectations about the severity of the illness and the side effects, helping them to manage their emotional wellbeing. Finally, dynamic content provided a cue to action, giving participants health management tips and strategies that they could immediately put into action.

The HBM also helps to explain participants' disuse of MyPath. The three participants who did not frequently read the recommended information described two HBM constructs: perceived severity and perceived benefits. When patients had strongly set beliefs that their illness was not severe they had little motivation to use the information. Managing external stressors, including comorbidities or the loss of a loved one, also seemed to reduce the perceived severity of the cancer diagnosis as well as the potential benefits of cancer-related information.

Table 8.3.1 provides an overview of the features used in the MyPath system to improve patient knowledge, the HBM constructs that were affected based on the participant interviews, and the subsequent actions that resulted from this intervention. Using the HBM to understand why MyPath influenced participants' behaviors helps us understand how the MyPath results may be generalizable to a broader patient population. My analysis suggests

that future systems ought to focus on reducing barriers to information seeking, helping patients set accurate expectations of their illness severity, and provide timely information in order to motivate immediate action. By influencing these constructs, I expect health interventions will encourage patient engagement in other contexts.

### 8.3.2 Design implications

By analyzing how and why MyPath helped patients become more engaged in their health-care, I have demonstrated the potential benefits of mobile tools that connect patients with personalized and adaptive content. However, there are many open questions regarding how personalization can best support an individual's health over time.

One important question that warrants future research is when should dynamic content be system-driven and when should a system include user-driven personalization. More automated tailoring could help reduce the responsibility placed on patients to recall and record their personal health issues. One promising technological approach is Just in Time Adaptive Interventions (JITAI). JITAI look at using sensing capabilities within a device to trigger an intervention [133]. In the context of connecting patients and health information, research could explore ways for technologies to monitor patient status, ranging from side effects to quality of life indicators. Such capabilities would have numerous health implications, providing real time feedback to doctors, as well as helping connect patients with information and tools to overcome side effects as they occur. Such systems could also be useful for identifying patterns of when side effects occur, helping patients to prevent their occurrence or severity. I expect that this technology could be particularly useful for those undergoing chemotherapy, when side effects are likely to occur within a select time after the weekly treatment.

My findings do suggest that mhealth tools should combine both system-driven and user-driven personalization. JITAI thus far have focused on system-driven interventions. However, user-driven adaptable content should also be included in these interventions. Patients

Table 8.1: Summary of MyPath features, study results, and the connections to constructs of the Health Belief Model

<b>MyPath Feature</b>	<b>Health Belief Model Construct</b>	<b>Resulting Action</b>
Aggregated online content recommended by oncologist	<b>Perceived barriers:</b> Information was viewed as both easy to access and reliable; reduced barriers to finding trusted information	Routine health information seeking
Personalized information about diagnosis and upcoming treatments	<b>Perceived severity:</b> MyPath became a tool for setting expectations regarding treatment and side effect severity	Managing emotional wellbeing
Dynamic information that adapts based on survey responses	<b>Cues to action:</b> Information provided strategies that could be used immediately to manage in the moment issues	Participants used information to motivate action, such as symptom management and talking to doctors

coping with cancer or other chronic illnesses face a number of challenges that may not be discovered through sensors. For example, many patients, including these participants, struggle with talking to others about a diagnosis. JITAIs may offer more comprehensive support by including mechanisms, such as the NCCN survey, to allow users to capture these issues and receive support. Further, combining both system-driven and user-driven personalization may help to improve the overall acceptance of the technology, as HCI research has indicated that users tend to prefer user-driven personalization [120].

JITAIs have only recently been discussed in the HCI community [134]. While interest in JITAIs has also emerged in the health informatics community [135, 133], HCI researchers are uniquely positioned to evaluate important issues regarding these interventions, such as the trust patients place in these technologies, and how they may be best designed to fit within the complexities of daily life.

Our analysis also reveals a way in which MyPath was less helpful to some participants. Specifically, that the personalized health information was ineffective when cancer was not the primary focus of the individual. The limitation highlights a need for research that considers what factors should be used to guide personalization of health information systems, which has also been discussed as an important area of research for developing peer support networks [136]. My results indicate that profiles should consider comorbidities, and help users find information related to all ongoing health issues. Further, systems should consider a patient's desire to find and use health information, though more insights are needed regarding how to best support patients who actively avoid potentially important health information. I expect other personal factors could be important input for systems that connect individuals with health content.

### 8.3.3 Limitations

The evaluation of MyPath includes limitations that must be addressed. First and foremost, the qualitative evaluation of MyPath focused specifically on the user-driven, adaptable con-

tent on MyPath, and not on the system-driven adaptive content that supports illness trajectory transitions. At the time of the interviews, participants had little to no experience with the adaptive content. This was primarily because participants enrolled during education day were already beginning treatment when they received the tablet, and were typically still in the same treatment when interviewed. Participants did comment that it would have been helpful to have the tablets earlier, as there is a long waiting period between diagnosis and beginning treatment. Based on this feedback I established a recruitment process that catches patients at diagnosis rather than education day.

Second, thus far no patients diagnosed with stage III or IV cancer have enrolled in the study. This omission was not due to any exclusion criteria, rather no patients with more severe diagnoses opted to enroll in the study. Finally, the MyPath study is biased as participants self-selected to participate in the study. I found that participants so far have been generally interested and proactive in learning about their disease and comfortable using technology. More research is needed about the extent to which self-selection influences HCI field studies and possible strategies to reduce this bias.

#### 8.3.4 Contributions

As the use of mobile tools for health continues to increase, important questions remain in how technologies can alleviate the burden of health information seeking, and help patients access information that considers both the breadth and dynamic nature of their information needs. In my evaluation I found that MyPath helps patients engage more directly in their care. Specifically, participants routinely used the application, which served as a catalyst for health management behaviors and supporting participants' emotional wellbeing. The theory-driven evaluation of these results indicate that systems offering personalized health information are beneficial due to their ability to reduce barriers to finding trusted and relevant health information, help patients manage expectations, and prompt health management tasks.

One goal with this work is to motivate the need for, and guide the design of, personalized health information systems in other health contexts. I expect such systems will be valuable to patients coping with other chronic illnesses, as they require similar patient engagement and personal health management. Systems such as MyPath may be particularly useful for patients who experience greater burdens in accessing the traditional healthcare system. Such patients include those in rural areas, minorities, and people of a low socioeconomic status.





## **CHAPTER 9**

### **DISCUSSION**

#### **9.1 The role of personalization in reducing barriers to care**

A central goal of my research has been to connect breast cancer patients to a comprehensive set of tools and information to support a diversity of patient work. Rather than using behavior change as a unifying framing, I have focused on reducing barriers to care by providing flexible tools that patients may adapt to fit their specific needs and challenges. I chose this focus as no single behavior is necessarily best when managing cancer, given the individuality of people's cancer experiences and health goals, and the range of obstacles that emerge throughout treatment and survivorship.

Similar to work supporting and evaluating behavior change [137], I believe the success of systems reducing barriers to care is best measured by evaluating the ability for the system to effect people's attitudes and beliefs, in addition to their actual behaviors. The MyPath study, which builds on the results of my formative work with cancer survivors and health professionals, provides an initial evaluation of how personalized health information systems can change health beliefs and influence health management behaviors. Interviews with participants touched on three health belief model constructs: perceived barriers, perceived severity, and cues to action. Each of these constructs have been used to predict health behaviors [138]. These results are important as they demonstrate an opportunity of personalized health information systems to influence patients' beliefs regarding their health situation.

A comparison of the MyJourney Compass and MyPath deployments also reveals the benefits of using personalization in health interventions. Two particular difference stand out when comparing the two studies. First, the results show a change in the frequency and

consistency in which participants engaged with the MyPath system. As I show in chapter 6, while use of the MyJourney Compass tablets continued throughout the year, the use of health-related content occurred primarily before treatment began.

Figures 9.1 and 9.2 provide a comparative use of the MyJourney Compass and MyPath systems by participants after beginning treatment, specifically radiation therapy or chemotherapy. The figure shows use of all MyPath participants and the MyJourney Compass participants who had treatment information accessible to the research team. The dots represent days in which participants used health information or content provided on the tablet device, and the grey bars show the total length of time that each participant owned the tablet. Due to the rolling recruitment, participants possessed the tablet for various lengths of time. The figure helps to show the clear difference in the way participants engaged with the MyPath system. Specifically, the weekly routine MyPath participants developed contrasted greatly to the sporadic use of health resources we commonly saw among participants in the MyJourney Compass study.

Most participants in the MyPath study stated that they used the application weekly because it was a step in their healthcare that they were responsible for, with several participants indicating that it was “what I’m supposed to do.” Interestingly, participants were not specifically told how or when to use the tablets. MyPath does include a weekly reminder to complete the survey though, as the questions focus on weekly events. This feature helped motivate patients to use the technology and develop a mental model of health information seeking that was more consistent than seen in the MyJourney Compass study. As I discussed in the previous chapter, engaging with personalized health information regularly helped to catalyze a variety of health management tasks.

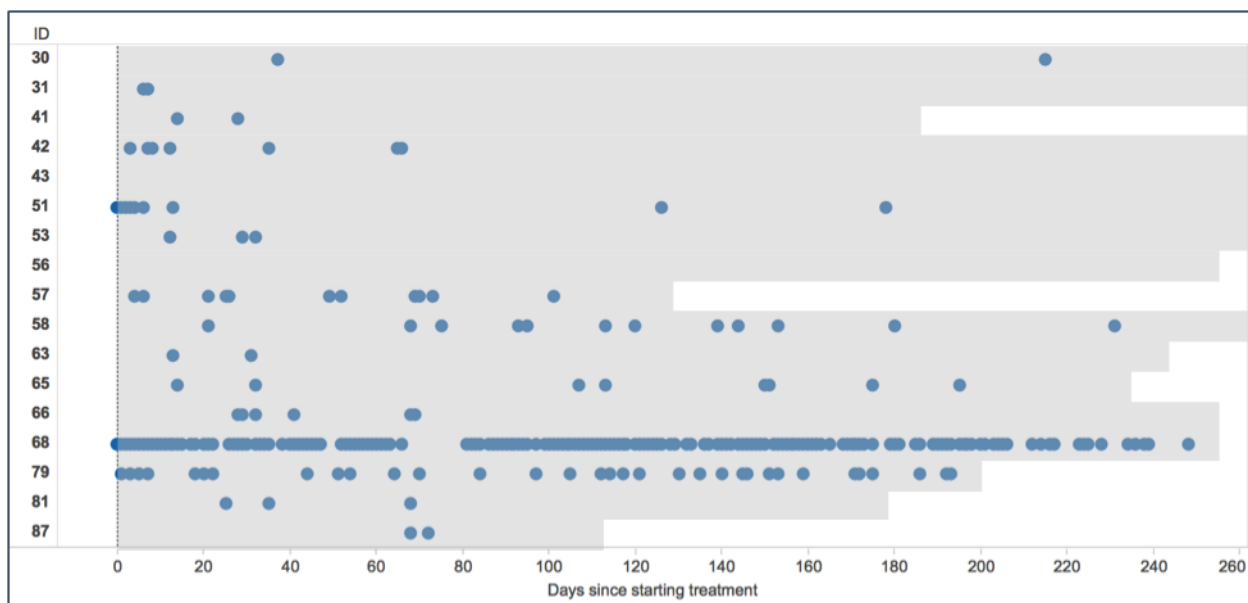


Figure 9.1: Use of MyJourney Compass Health Content After Beginning Treatment

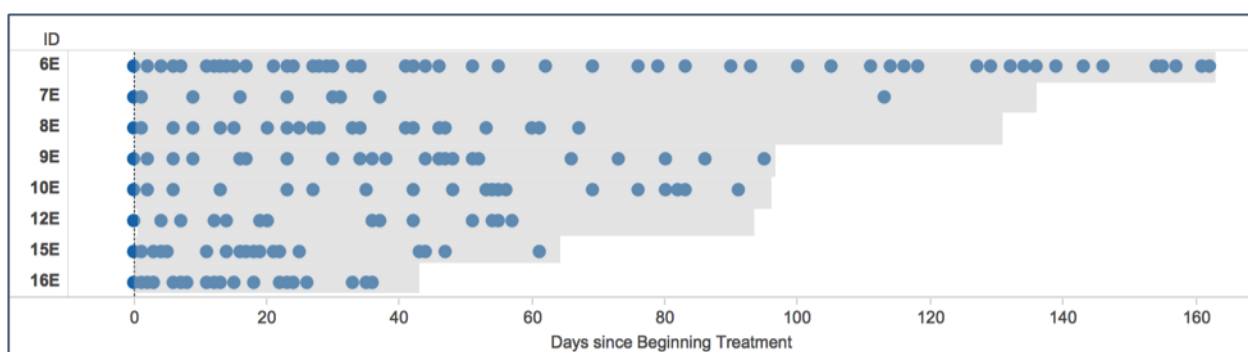


Figure 9.2: Use of MyPath Health Content After Beginning Treatment

Another difference between the two deployments was in discussions about how technologies could be improved to support patients needs. In the MyJourney Compass project, we had very few responses to this question. Participants generally stated that they had the tools they needed, and they couldn't think of much else technology could do to help them. However, within the MyPath interviews, participants were much more engaged in conversations about technology improvements. I found that by providing a small level of personalization, I changed participants' expectations of the technology. Participants wanted survey questions that were tailored to their treatment path and information that considered

all of the health issues they were coping with. Therefore, providing individuals with an example of personalized systems can be an important step in engaging them in the design of future health tools.

## **9.2 Generalizability of results**

My research has specifically focuses on the needs of breast cancer patients in a rural Georgia community. However, more broadly my research offers approaches for developing tools that support individuals whose health information needs are broad, diverse, and change over time. These challenges are not specific to breast cancer. Research studying illness trajectories and chronic disease management show the pervasiveness of health information seeking and self-management challenges. Across chronic illnesses, patients become responsible for a number of self-care tasks [40], struggle with changing health situations [139, 140], face numerous barriers to finding and using health information [141, 26], and must take on new health management behaviors [2]. Thus, the need for personalized information and support spans across many illness trajectories.

A review of the literature showed that self-management classes are considered an important support mechanism across a wide array of chronic diseases [41]. Self-management interventions (which thus far have focused on in-person education, rather than technological interventions), have demonstrated benefits similar to the MyPath study. Specifically, they have been effective in improving patient knowledge and “performance of self-management behaviors” (p.181). Thus, technological interventions, such as MyPath, may offer a new approach to supporting and improving patients’ health management that is less costly than traditional self-management classes.

Some original findings that contribute to our understanding of how mobile tools may support self-management include the value in allowing patients to modify health tools to meet their personal needs. Many studies have focused on how patients use single healthcare applications. My research addresses the need for patient-centered technologies to become

more general-purpose tools. Considering both health and personal uses when designing technologies will allow patients to more easily access the benefits of health technologies while also supporting the natural transition between focusing on health and daily life. Also, I have demonstrated that personalized content can make health information more manageable and actionable, thus directly influence patients' health management behaviors. I also confirmed findings in other studies, such as the ability for technology to enhance patient-provider communication and help patients organize logistics and personal health information during treatment. Further, as I discussed in chapter 3, the methods I have used to understand patient needs may be of use in other health contexts. Looks at aggregating experiences and practices from patients, providers with a specific focus on change over time.

### **9.3 Impacts to the existing healthcare system**

An interesting outcome of my research is that it demonstrates the ability for HCI research to directly change an existing healthcare system. In planning the field deployments with the Harbin Clinic and cancer navigators, we decided that the recruitment and technology support would be best handled by a cancer navigator, in order to respect the emotional burden placed on newly diagnosed cancer patients. In order to accommodate the new responsibilities, the navigation organization developed the new education navigator position, thus, changing the institutional structure of the navigation system. The education navigator provided participants with technological support from an organization they already knew and trusted.

Partnering with cancer navigators also provides a new strategy for recruiting in oncology, a challenge for many researchers as little infrastructure exists to support recruitment for HCI studies. Working with organizations like the cancer navigation group allows researchers to respect the emotional challenges faced by a vulnerable population at a challenging time while at the same time gaining the trust of their participants.

In reflection, this change to the organization was largely possible due to my collaboration with the navigation organization from the onset of the research. The early partnership allowed the navigators to feel a sense of ownership over the research. I have found that the education navigator role provides benefits to the healthcare system extending beyond the research. Specifically, the education navigators allow the navigation organization to expand its own technology fluency. Such fluency will allow the organization to better support patients as patients incorporate technology in their healthcare, an expected outcome irrespective of this study's implementation.

While this organizational change addresses a need specific to the healthcare system in which I was working, it also addresses the more general need for greater navigational support across the nation. My work offers a case study demonstrating the importance for researchers and healthcare practitioners to collaborate in an effort to enhance both the research and the healthcare systems.

## **9.4 Future work**

There are many interesting ways to expand upon this research. I first discuss basic feature improvements I believe would benefit the MyPath system. I then discuss two possible research paths, one focused on extending the functional capabilities of personalized health tools, and one aimed at developing personalized support for other illness trajectories.

### 9.4.1 Connecting personalized health information system use to psychosocial metrics

An open question regarding how use of MyPath influences patients' cancer experiences over time. To answer this question, a randomized controlled trial (RCT) of the MyPath system is currently ongoing. The trial compares use of the MyPath system with a baseline group of patients with no tablet application, and a control group that receives a static version of MyPath. A number of psychosocial metrics are being collected during the RCT, including participants' self-efficacy, health locus of control, and quality of life.

This trial will allow us to explore a number of research questions related to MyPath use and influence on psychosocial metrics. These questions include: 1) For each psychosocial metric, does the mean change at 0,2,4, and 6 months? 2) For each psychosocial metric, is there a significant difference between the three study groups? 3) Does frequency of use, number of survey responses, or total time using MyPath correlate to changes in psychosocial metrics? Collectively, these questions will help provide evidence into how and why personalized health information systems influence patients cancer experiences.

#### 9.4.2 MyPath system improvements

There are two system features that I believe would greatly benefit the MyPath system, or similar tools, in the future. First, the application would benefit from search capabilities. Providing search features could help users more easily find information related to specific health questions, such as details about a specific drug or therapy. Further, the search functionality could offer users a mechanism to view health information not already recommended to them, thus helping patients find information about future treatments or information for other people, which was a common use of the MyJourney Compass system.

Health information systems could also benefit from giving users greater control over the organization of resources. Within the MyPath application, I would provide users with the ability to delete and move information. This improvement was not directly discussed in interviews, but prior work has indicated user preference over systems in which they have greater control [120].

#### 9.4.3 Expanding on technical capabilities of personalized health tools

There are many opportunities in this area of research for collaborations within computer science, including machine learning and natural language processing, to develop patient classifications that utilize comprehensive journey data that extends beyond one's physical health and create systems that can offer automated personalized support. As I mentioned

in the last chapter, developing more automated personalization can help decrease the responsibility placed on patients to recall and input challenges. JITAIs offer one potential strategy for using the sensing capabilities on everyday tools to identify health issues, such as common side effects, and deliver timely support.

#### 9.4.4 Designing for other illness trajectories

An important question in offering dynamic support to patients is how we may design tools for illness trajectories that are characterized by extreme variability and unpredictability. Unlike cancer, in which patients progress through common phases of care, degenerative diseases, such as Parkinson's disease, are less structured and patients face varying rates of progression. Thus, a difficult question is how technology may offer personalized health information for more unpredictable chronic illnesses. An in-depth analysis of the patient experience, clinical care, and technology use will help in determining the unique barriers to care that characterize these illnesses, patients' information needs over time, and ways in which technology may better support individuals' changing needs and goals. Such work would help to extend research characterizing the different progressions of chronic diseases [20], by differentiating the important technological support systems and approaches for various illness trajectories.



## CHAPTER 10

### CONCLUSION

In my research, I evaluate the hypothesis: *flexible and adaptive mobile technology, informed by existing care practices and patient experiences, will help patients manage complex healthcare trajectories by motivating health management behaviors specific to one's individual needs.*

Guided by formative studies with oncologists, cancer navigators, and breast cancer survivors, I first developed MyJourney Compass to test the benefits and limitations of flexible health management aids, that allow participants to modify content and user freely. Notably, this technology probe demonstrated that by allowing participants to add their own content, participants remained engaged with the technology over time, with many using the devices after completing treatment. This engagement encouraged participants to return to using the cancer-specific content when new questions arose. Participants used the technology in a variety of ways to meet their personal needs and goals, such as using Youtube to learn how to cook healthier meals, and playing games during chemotherapy to stay calm during treatment. Ultimately, this work highlights the value of developing health tools that are open, allowing patients to modify the included resources.

I also found during the MyJourney Compass technology probe that use of the health information declined once participants began treatment. I developed MyPath to reduce barriers to finding and using health information across the cancer journey. The evaluation of MyPath demonstrates the benefits and limitations of connecting patients with personalized health information. Within the MyPath study, I found that participants developed very different usage patterns than with MyJourney Compass. Participants developed a routine in which they engaged with the health information weekly. Further, participants revealed a number of ways in which the personalized health information recommended through My-

Path did influence health behaviors, such as encouraging patient-provider communication and side effect management. Use of the Health Belief Model in the analysis suggests that use of the technology influenced patients' health beliefs regarding illness severity and barriers to learning about one's health. These changes in perspective motivated use of the health information and the various health management tasks that participants described.

The MyPath study also revealed opportunities for future research. In particular, unlike the participants in the MyJourney Compass project, MyPath participants came up with many ideas for enhanced personalized content. In particular, participants shared a desire for tools that provided information for comorbidities, and how to effectively management them in parallel.

Collectively, my work makes a number of contributions to the HCI and health informatics communities.

*Health informatics:* For health informatics, my first research offers a detailed understanding of cancer patient's information needs, and how they change over time. Many studies have looked at understanding the breadth of patient challenges, but I found little work exploring how these issues change as patients progress through the cancer trajectory. With the cancer journey framework I present details on how patients' responsibilities and challenges change as an individual progresses from diagnosis, through treatment and post-treatment survivorship.

My research also identified how patients' and healthcare professionals' preferences differ regarding health information sharing. I discussed strategies in which these discrepancies may be revealed within care practices. Helping patients and providers understand these difference is an important step for improving patient-provider communication, improving patient satisfaction, and ensuring important patient needs are not overlooked by their healthcare providers.

Finally, my research provides insights into technology features that encourage positively influence health management. Many tools studied in health informatics, such as

personal health records, focus on connecting patients with their personal data. My work highlights the need for tools that help connect patients to a broader set of resources. The MyPath study in particular demonstrates the value of tools that connect patients to health information tailored to their specific treatment path and personal needs.

*Human-computer interaction:* For the HCI field, my research provides a number of design guidelines, informed by existing care practices, for tools that support long-term health issues. In particular, this work calls for tools that are personalized and modifiable- providing patients with more autonomy to manipulate the technology to meet both their health and personal needs. I have also outlined a number of strategies in which HCI researchers and technology could better support navigation practices directly. As I discussed in the previous chapter, my work also presents a model for partnering with cancer navigators to inform and improve HCI design and deployments, and provides an example of how an HCI project can directly influence an existing healthcare practice.

In my work I also provide an evaluation of the usability of personalized, dynamic content in a health context. Few studies have considered issues of information access and trust of personalized content within a health setting. My work demonstrates that dynamic content did not negatively influence access to health information, and that the technology provided an ease of access and trust that complemented cancer navigation practices and exceeded other information sources.

The MyJourney Compass and MyPath prototypes are themselves contributions to the HCI field. These novel systems both provide patients with tools that support both a diversity of needs and offer the flexibility to adapt as patients needs change over time. Few systems have considered time as a critical component in patient health tools. These two systems provide models for designing technology that consider changes over time. Further, the evaluations of these systems demonstrate the ability for such technology to engage patients over time and influence health behaviors.

Finally, my work provides a set of methods that modify commonly used qualitative

methods to analyze change in healthcare experiences and practices over time. This contribution may be of value to both the health informatics and HCI communities. Such methods are important as chronic diseases become increasingly pervasive. Both communities are focusing on a variety of chronic illness experiences and support mechanisms. However, little guidance exists within either community for how to evaluate how these experiences change over time. The methods I have used and reflected on in this dissertation provide a model for focusing on change over time that may be used to guide other research studies.

# **Appendices**



## APPENDIX A

### MYJOURNEY COMPASS SYSTEM FEATURES

The MyJourney Compass tablets included a set of resources that were chosen by a team of oncologists, cancer navigators, and breast cancer survivors. These resources included health and cancer-related applications and websites, as well as PDF information from Harbin clinic and contact information for patients' healthcare providers and cancer navigators. Figure A.1 shows a screenshot of the MyJourney Compass tablets.

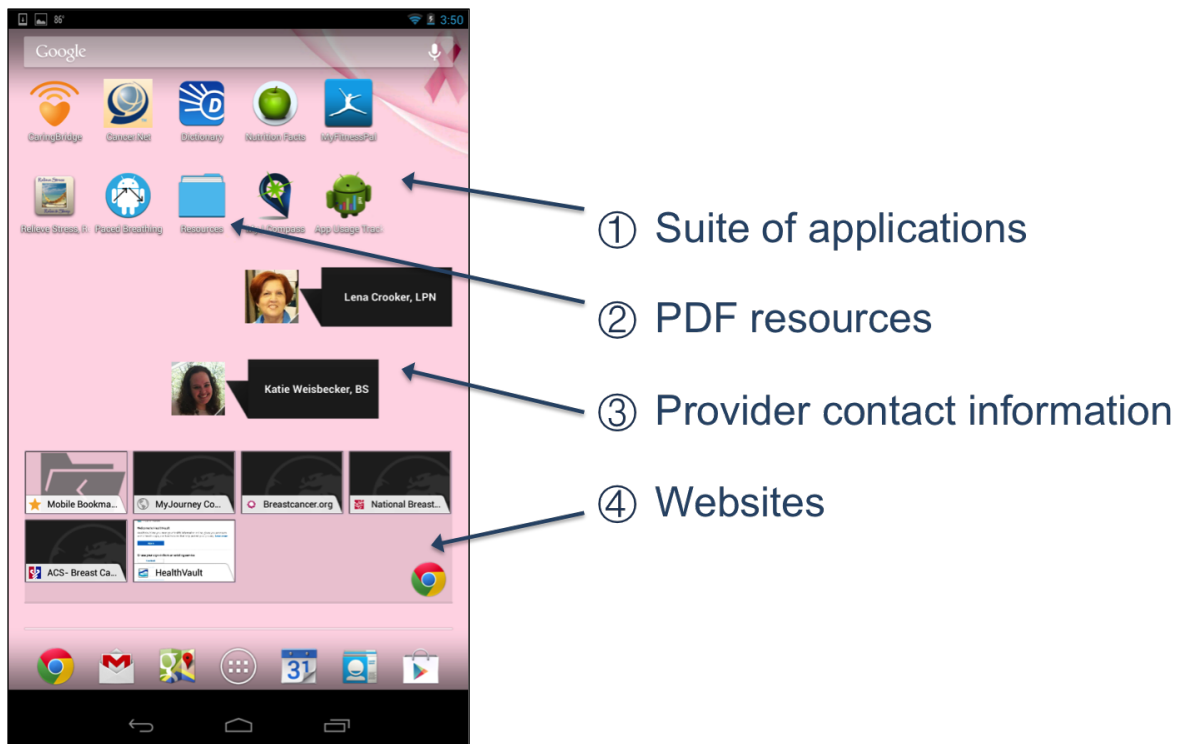


Figure A.1: MyJourney Compass System Features





## **APPENDIX B**

### **MYPATH SYSTEM FEATURES**

The MyPath application screens and features are shown in figures B.1 - B.8. Before a patient receives a tablet with the MyPath application, the education navigator completes a user profile, which drives the personalized content. The profile includes diagnosis and treatment information, as shown in figure B.1. New resource recommendations then appear for each patient and regularly update as a patient begins new treatments. Figure B.2 shows what the main page of MyPath looks like when there are new resources recommended in the application. Figure B.3 shows a sample list of resource recommendations in the Treatments category, and figure B.4 shows a sample article included within the application.

The MyPath survey may also be completed by patients to receive timely information about existing issues they encounter as they progress through treatment. Figures B.5 and B.6 show screenshots from this survey. Once a patient completes a survey, the message shown in figure B.7 appears to tell them that new resources have been added to their MyPath application based on the survey responses. Figure B.8 shows the MyPath main page that has been updated with new resource recommendations.

Study Settings SAVE

Cancer Type  
**Optional**

Cancer Stage  
**Stage 2**

Gender  
**Female**

**TREATMENTS**

Chemotherapy ☒ Chemotherapy is anticipated  
Start date  
**Mon, 7 Aug 2017**  
End date  
**Mon, 30 Oct 2017**

Radiation ☐ Radiation is anticipated  
Start date  
End date

Hormone Therapy ☒ Hormone Therapy is anticipated  
Start date  
**Wed, 15 Nov 2017**  
End date

Figure B.1: MyPath user profile

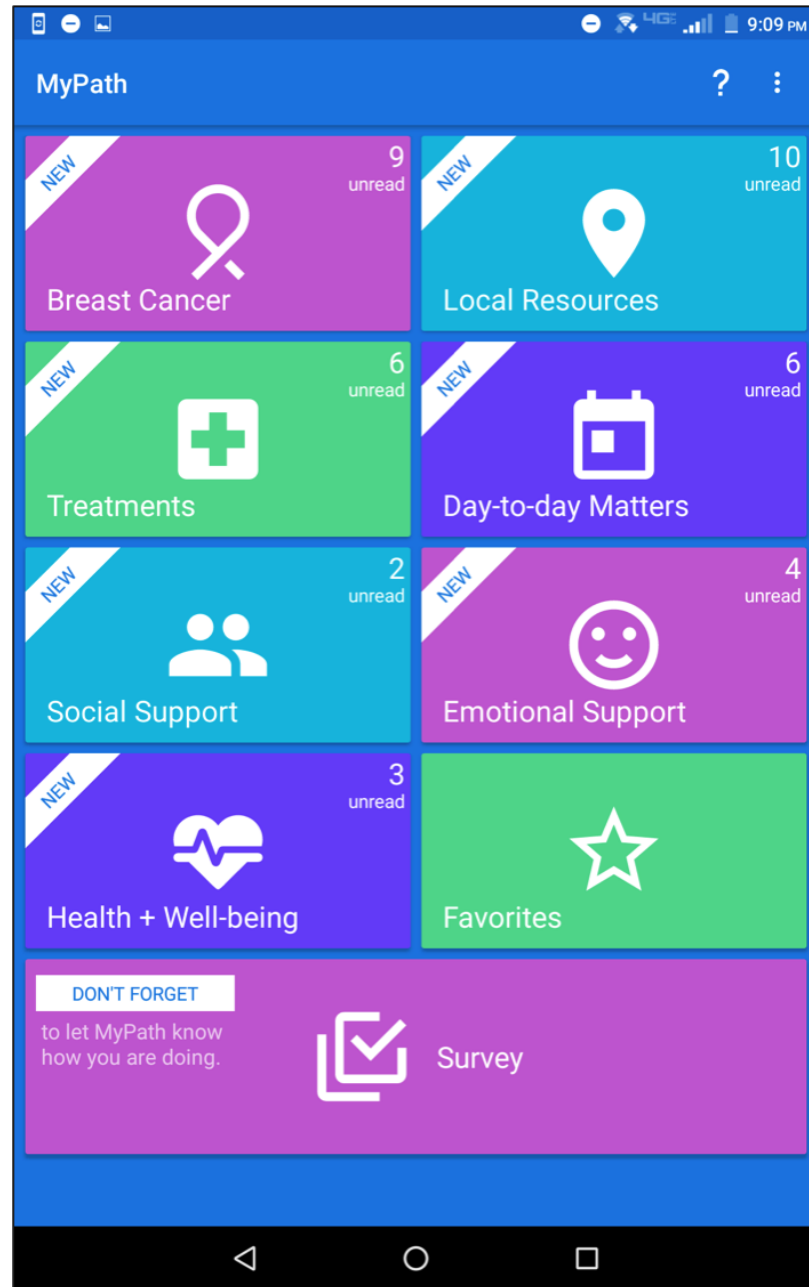


Figure B.2: MyPath main page with new resource recommendations

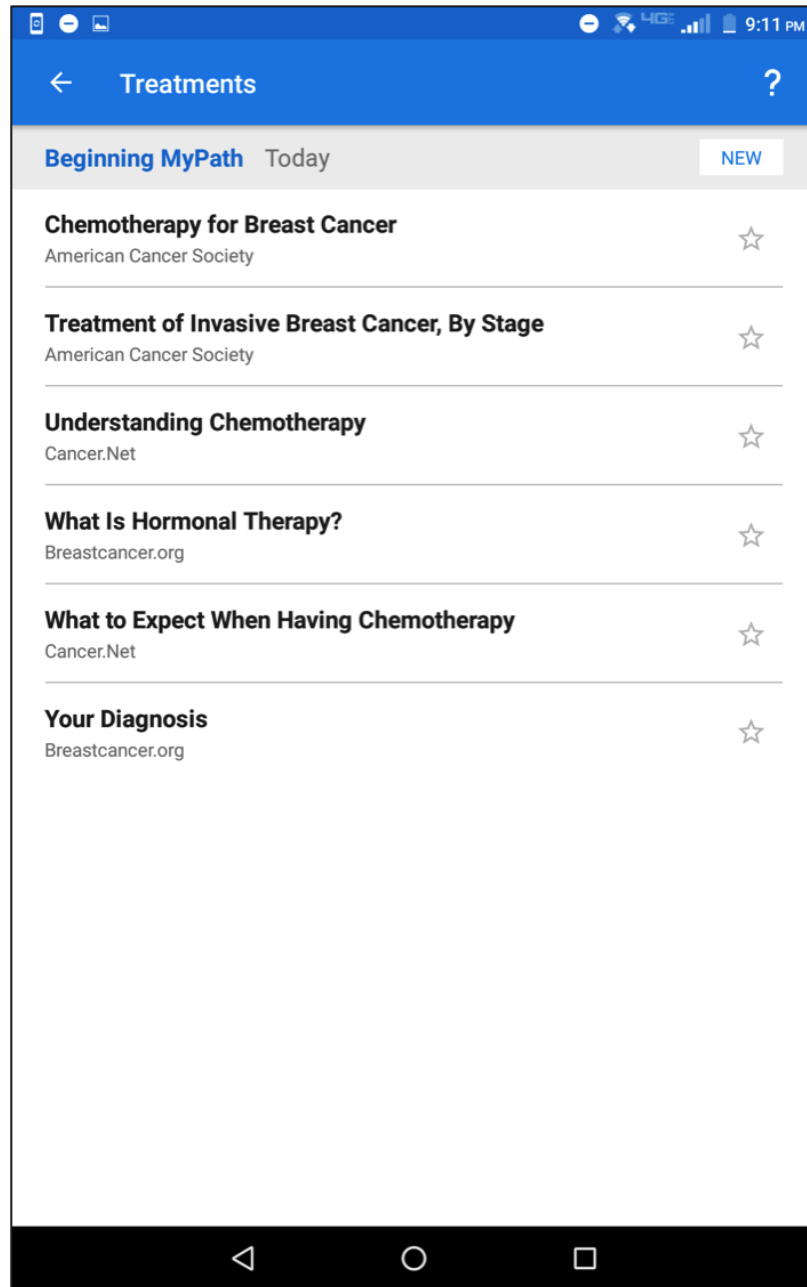


Figure B.3: Sample set of personalized recommendations

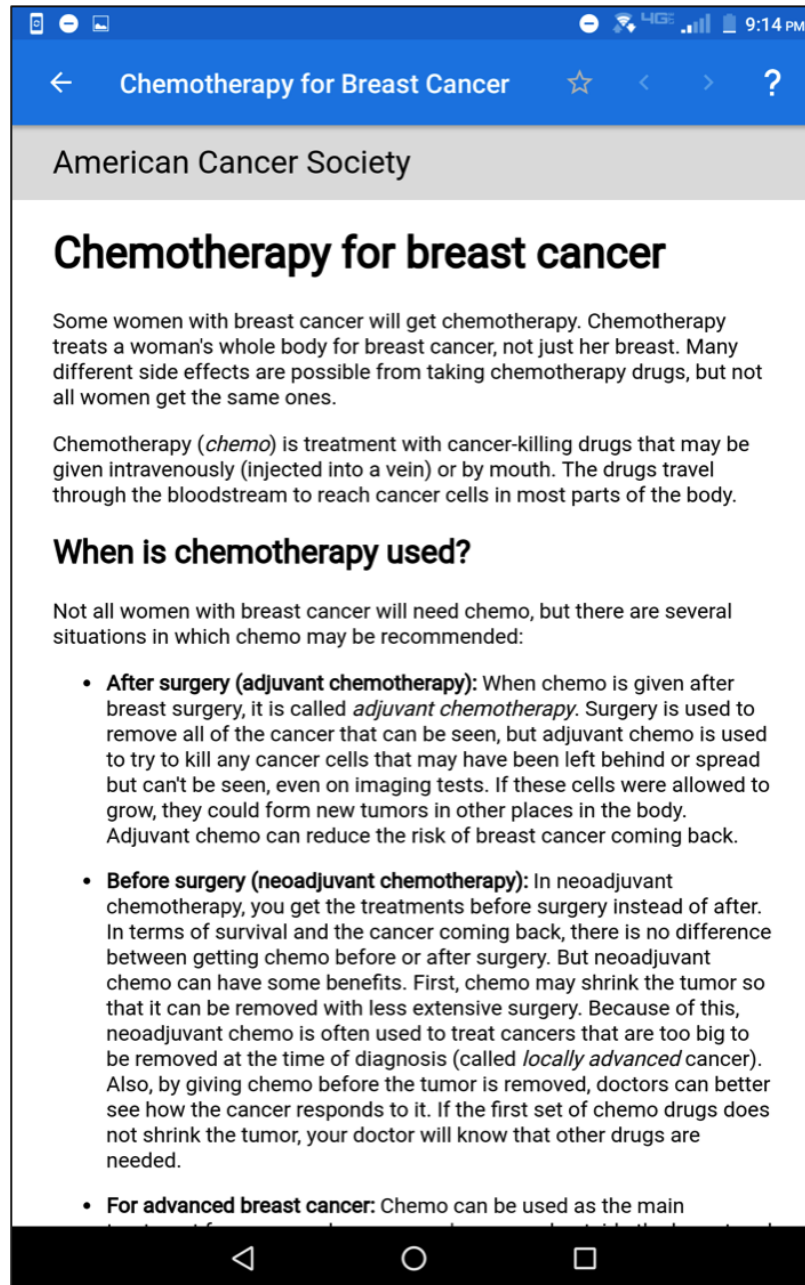



Figure B.4: Example article recommended in MyPath

Survey

?

 This survey will allow MyPath to suggest resources you may find helpful.

How much distress have you been experiencing in the past week including today?

0

No distress

10

No distress

Extreme distress

→

Figure B.5: MyPath survey: question 1

Survey

Have any of the following been a problem for you in the past week, including today?

Day to Day Matters

- ☐ Child care
- ☐ Housing
- ☐ Insurance / financial
- ☐ Keeping pets
- ☐ Talking to doctors
- ☐ Time management
- ☐ Transportation
- ☐ Treatment decisions
- ☐ Work / school

→

Figure B.6: MyPath survey: question 2

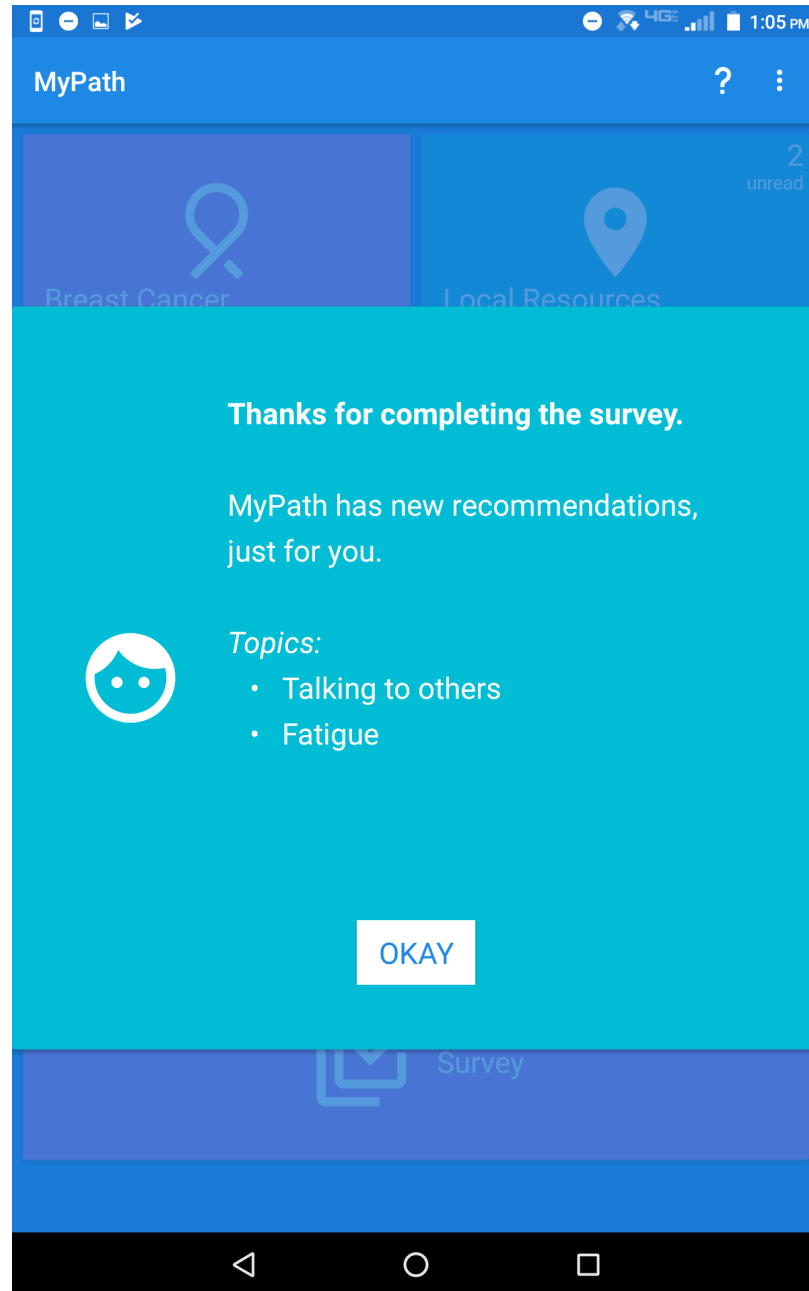


Figure B.7: Message that appears after completing a survey in MyPath



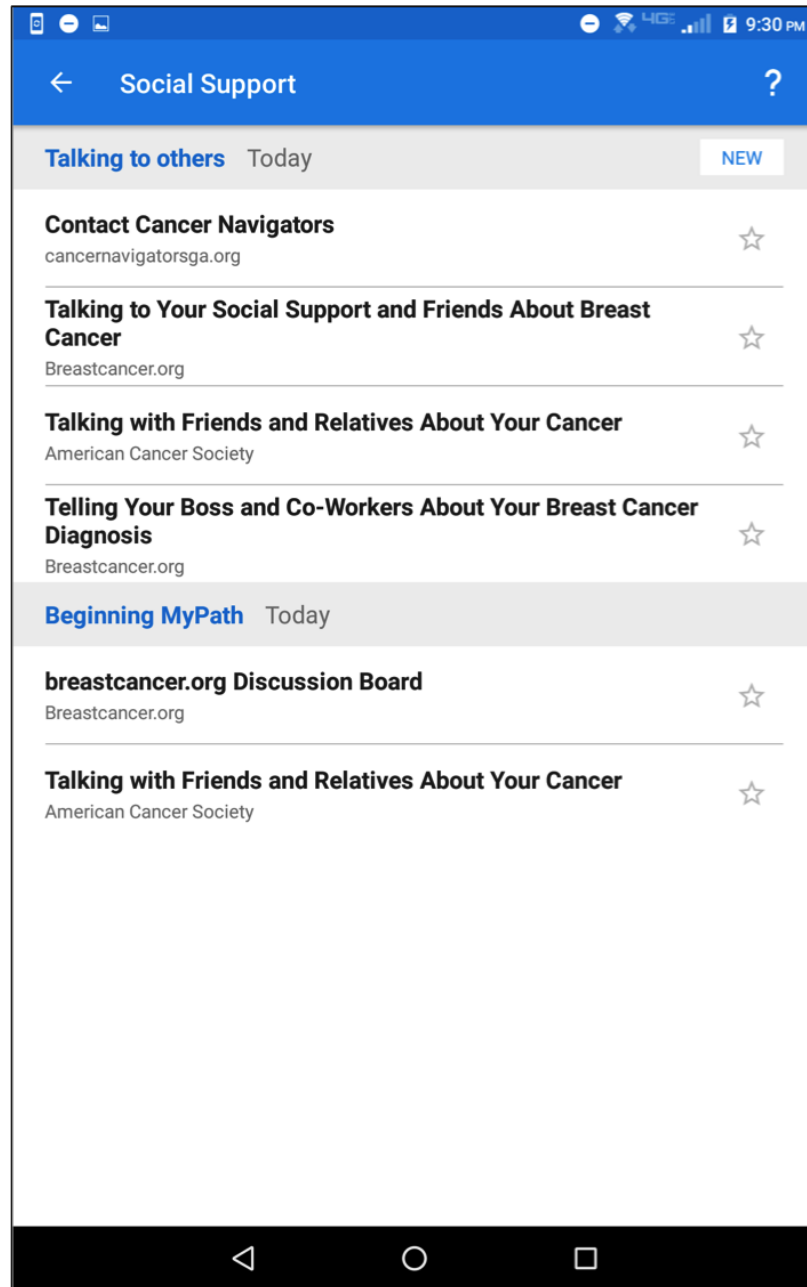


Figure B.8: Updated resource recommendations after survey completion

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